

**Coming out of the Shadows:  
The Psychological Impact of  
Childhood Cancer on  
Healthy Siblings**

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the requirements for the degree of  
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## **DECLARATION**

“I certify that this is a true and accurate account of the work carried out. This thesis has been composed by myself and the work herein is my own.”

“The work herein has not been submitted for any other degree or professional qualification”

***Dedicated Always & Forever To***

**Maureen J Macleod  
George & Elma Stephen**

***Three More Angels in Heaven  
Three More Stars in the Sky***

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## **ABSTRACT**

**Introduction:** With the increased survival rates for childhood cancer, the disease is now typically viewed as a chronic rather than a terminal illness. This has resulted in changes in the impact of the disease as experienced by the whole family unit.

**Objectives:** To investigate the psychological and behavioural effects of childhood cancer on healthy siblings of children with cancer compared with a control group.

**Design:** An independent-group design was employed to compare the results from healthy siblings of children with cancer to a control group.

**Methods:** Parents and healthy siblings in the oncology and control group were asked to complete questionnaires/measures regarding the psychological and behavioural functioning of the healthy siblings.

**Results:** Healthy siblings of children with cancer were not found to exhibit significantly more behavioural problems than children/adolescents in a control group. They did however rate themselves as being significantly more depressed than participants in the control group. Age and gender were found to have significant effects on the behaviours of healthy siblings of children with cancer. Parents in the oncology group were significantly more depressed than were parents in the control group. The Behaviour Problems and Social Competence scores of healthy siblings of children with cancer were found to be predictors of parental depression. Results are discussed in relation to previous research findings.

**Conclusions:** Healthy siblings of children with cancer and their parents were at an increased risk of experiencing psychological and behavioural problems compared to a control group. Clinical implications, in light of these findings, are discussed. Strengths and limitations of the present study are addressed and areas for future research are explored.

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## **CHAPTER ONE - INTRODUCTION**

## 1.1 GENERAL INTRODUCTION

The following chapter explores the background research and rationale for examining the impact of childhood cancer on healthy siblings <sup>1</sup>. A general overview of childhood cancer is initially presented. This overview identifies definitions of cancer, the prevalence of childhood cancers, types of childhood cancer and treatment approaches to this disease. The potential side-effects of the different treatments are also explored. The way in which the face of childhood cancer has dramatically changed with medical advances and technological developments is also addressed. With increasing survival rates of childhood cancers, the disease is increasingly being viewed as a chronic rather than terminal illness (Selby & Bailey, 1996) <sup>2</sup>. Consequently the short, medium and long-term effects of childhood cancer for both the ill child and their family are becoming increasingly more important <sup>3</sup>. The introduction explores the way in which childhood cancer impacts on a.) the ill child and b.) their parents.

The section examining the research on the effects of childhood cancer on healthy siblings<sup>4</sup> begins by outlining research on the sibling relationship. It has been widely recognised that the impact of childhood cancer on healthy siblings is often overlooked, both clinically and within the research (Dennis, 1995; Harding, 1996). The negative sequelae of childhood cancer on healthy siblings are explored (such as cognitive, emotional, physical and behavioural difficulties). Whilst it is important to recognise the potential negative consequences of childhood cancer on healthy siblings, it is also necessary to acknowledge that there may also be positive consequences.

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<sup>1</sup> It is recognised that there are a number of different types of childhood cancers. Unless otherwise specified the general term cancer will be used to describe all types and severity of cancer.

<sup>2</sup> Williams (1997) defined a Chronic Illness as being "...a medically diagnosed ailment with a duration of six months or longer, which shows little change or slow progression." (pg. 312).

<sup>3</sup> The term 'child' and 'children/adolescents' are used throughout this research to refer to individuals aged 0 to 18 years. The terms 'parent/parents/parental' are used to refer to parents/carers/guardians.

<sup>4</sup> Healthy Siblings are defined as those children/adolescents who do not have cancer or any chronic or acute illness.

Whilst some healthy siblings of children with cancer exhibit marked difficulties, others demonstrate adaptive adjustment and personal growth as a result of their sibling's illness (Dolgin & Phipps, 2000). A number of factors have been found to mediate the impact of childhood cancer on healthy siblings (Williams, 1997). Such factors include: illness characteristics (e.g. type and severity of cancer diagnosis and treatment), individual characteristics of the healthy sibling (e.g. age, gender and personality), family characteristics (e.g. socio-economic status, family communication and family relationships/dynamics), parental characteristics (e.g. the emotional functioning of the parent of the healthy sibling) and social characteristics (e.g. cultural context and availability/access to social resources and support).

The sibling relationship has been found to be of significant developmental importance (Dunn, 1988), with the diagnosis of childhood cancer having a major long-term effect on the healthy sibling's development (Murray, 1998). The potential cognitive, social and emotional consequences of childhood cancer for healthy siblings are examined. One of the recognised difficulties inherent within the research into the impact of childhood cancer on healthy siblings is the recognition that the needs of this population are often under-estimated and under-treated. Rationales for difficulties in recognising the impact of cancer on healthy siblings are explored. Methodological weaknesses inherent within previous research limit the extent to which comparisons can be made across the research and limit the generalisability of much of the previous research literature (Lehna, 1998). Such methodological problems are discussed and a framework for a more reliable and valid research study is explored. The introduction chapter concludes by outlining the aims, rationale and hypotheses of the present research study.

## 1.2 GENERAL OVERVIEW OF CHILDHOOD CANCER

### 1.2.1 Definition of Cancer

The human body consists of many millions of cells. Cancer is a disease which involves the abnormal uncontrolled growth of cells, which can affect and invade any organ system or area of the human body (Granowetter, 1994). There are two types of tumours: benign tumours (i.e. non-cancerous) and malignant tumours (i.e. cancerous). Cancer is not a homogenous disease, but consists of three principal types; a.) carcinomas which originate in tissue cells, b.) sarcomas which originate in connective tissue, bone and muscles and c.) leukaemia which originates in bone marrow (Pinkerton & Plowman, 1997).

### 1.2.2 Prevalence of Childhood Cancers

Childhood cancer is a relatively rare disease (Miller, Young & Novakovic, 1995). Approximately one hundred and twenty new cases of childhood cancer are diagnosed per year in Scotland (Campbell, Wallace, Bhati, Stockton, Rapson & Brewster, 2004). It is estimated that by 2010 one in 715 of the adult population will be a long-term survivor of childhood cancer (Scottish Intercollegiate Guidelines Network (SIGN), 2004). Cancer constitutes the largest non-accidental cause of death in children aged 2 to 16 years (Bearison & Mulhern, 1994). Table 1 illustrates the epidemiology of childhood cancer in the United Kingdom.

**Table 1 Cancer Incidence (rates per 1,000,000 person) by Age Group (0 – 14 years) (Selby & Bailey, 1996).**

Diagnostic Group	Age Group			
	0	1 – 4	5 – 9	10 – 14
Leukaemia	27	65	30	20
Lymphomas	4	7	12	15
Brain & Spinal Tumours	19	27	25	21
Bone Cancer	0	1	4	10
Retinoblastoma	17	7	0	0
Rhabdomyosarcoma	7	6	5	5

### 1.2.3 Types of Childhood Cancer

In contrast to adults, there is great diversity in the histological type and primary sites of cancer in children and adolescents (Selby & Bailey, 1996). As suggested in Table

1, one of the most common types of childhood cancer is leukaemia. This type of cancer manifests itself as disorders of blood cell production (Granowetter, 1994). Acute Lymphoblastic Leukaemia (ALL) is the most common type of childhood leukaemia, accounting for 80% of all childhood leukaemia (Kazak & Nachman, 1991). A further form of cancer, Acute Nonlymphoblastic Leukaemia (ANLL), also called Acute Myeloid Leukaemia (AML), affects all blood forming cells, with the exception of lymphoblasts. Tumours are a form of cancer that cause harm by excessive local growth or by metastasis (Granowetter, 1994). Hodgkin's Lymphoma (HL) and Non-Hodgkin's Lymphomas (NHLs) is cancer that originates in the lymph node-bearing areas. Wilm's Tumour is a form of embryonic tumour and is therefore an illness that predominantly affects children. (Granowetter, 1994). Neuroblastoma is a paediatric neoplasm, typically located in the abdomen or chest. Osteosarcoma is a cancer of the bones, as is Ewing's Sarcoma, whilst Retinoblastoma is a cancer of the eye. Rhabdomyosarcoma is a soft tissue tumour.

#### **1.2.4 Aetiology of Childhood Cancer**

Numerous causes have been proposed in order to account for the incidence of childhood cancer. Due to the geographical clustering of certain types of cancers in particular areas (such as the high prevalence of childhood cancers close to nuclear power stations at Sellafield and Dounreay) some researchers have argued that environmental factors play a causal role in the occurrence of the disease (Pinkerton, Cushing & Sepion, 1994). Selby & Bailey (1996) likewise argued that environment played a part in causing cancer when they demonstrated that there is a geographical difference in the clustering of cancer in America and Western Europe compared to Central and Eastern Europe. The characteristic pattern of cancer in the west is low rates of childhood cancer and higher rates of adult cancer whereas in the east the pattern of cancer for adults is the same but there is a higher prevalence of childhood cancer.

Other hypotheses proposed to account for the incidence of childhood cancer include:

- genetic/family history (Selby & Bailey, 1996)
- seasonality effect (with an excess number of cases diagnosed in the winter) (Selby & Bailey, 1996)
- socio-economic status (especially in ALL where the disease is more prevalent amongst higher socio-economic families) (Campbell et al. 2004; Doll, 1991)
- exposure to carcinogens (such as street drugs, toxins, pesticides and infections) (Alexander, 1993; Pinkerton et al., 1994)
- exposure to nuclear radiation (Shimizu, Schull & Kato, 1990)
- maternal fertility problems and assisted conception (Pinkerton et al. 1994)
- birth characteristics (such as maternal age, birth weight and birth stature) (Draper, Vincent, O'Connor & Stiller, 1991)
- parental occupation (Granowetter, 1994).

Inconclusive findings have been found with regards to maternal ante and post-natal smoking (Tredaniel, Boffetta & Little, 1994). Unfortunately much of the research, discussed above, into identifying the aetiology of childhood cancer has proved to be inconclusive due to the limited number of participants involved in studies. From the research, it appears unlikely that there is one overall causal factor, but rather the cause of childhood cancer is typically viewed as involving a complex interaction between a number of different predisposing/precipitating factors.

### **1.2.5 Treatment of Childhood Cancers**

Whilst historically the goal of childhood cancer treatment was support and palliative care, now the goal is total cure, with the minimisation of toxicity and the preservation of quality of life (Alcoser & Rodgers, 2003). In the United Kingdom and United States the current survival rate for a child/adolescent diagnosed with cancer is approximately sixty percent (Stiller, 1997). Previously, once a child has been diagnosed, surgery would have been the only treatment option, however with medical advances a number of different therapeutic approaches are now available in the multi-modal treatment of childhood cancer (Alcoser & Rodgers, 2003). Treatment is likely to be variable and extended (Shapiro & Brack, 1994), with the



average length of treatment for childhood cancers being three to four years (Kazak & Nachman, 1991) and involving inpatient and outpatient care (Shapiro & Brack, 1994). Types of treatments of childhood cancer include a.) Chemotherapy, b.) Radiotherapy and c.) Surgery (Granowetter, 1994).

**a.) Chemotherapy**

Chemotherapy is the primary treatment modality for childhood cancer and involves the administration of cytotoxic agents (i.e. drugs that are toxic to cells) (Pinkerton et al., 1994). Cytotoxic agents act by interfering with division and growth of cells and normal cell metabolism (Granowetter, 1994). The three main aims of chemotherapy are: i.) reduction in tumour size, ii.) destruction of cancer cells and iii.) prevention of metastases. Chemotherapy can be administered in a number of ways; intravenously (into a vein), orally (by mouth), intramuscularly (into muscle) and subcutaneously (under the surface of the skin). Chemotherapy may be the first course of treatment of cancer, or it may be employed post-surgery to eliminate any residual malignancies (Friedman & Mulhern, 1991). Although chemotherapy is one of the standard therapeutic agents for the treatment of cancer, there are a number of potential side-effects of this treatment, including; nausea, vomiting, diarrhoea, anaemia, hair loss and cognitive deficits (Bauld, Anderson & Arnold, 1998). Chemotherapy causes particular damage to areas of the body where normal cells rapidly divide and grow (e.g. the digestive system, skin, hair and mouth).

**b.) Radiotherapy**

Radiotherapy is typically used in collaboration with other treatment modalities and involves the delivery of ionising radiation in order to destroy the cancerous cells (Pinkerton et al., 1994). Radiotherapy causes structural changes to the body's organs, soft tissue and bones (Koocher & O'Malley, 1981). Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) are employed to ensure the precise delivery of radiation to the tumour site. Whilst radiotherapy can be an effective treatment agent, it can potentially cause significant damage to the healthy cells located close to the tumour. Early side-effects of radiotherapy can include: bone marrow depletion, increased susceptibility to infection, hair loss, nausea, vomiting, loss of appetite, skin reactions (e.g. burns) and increased intracranial pressure. Long-term side-effects of radiotherapy can include: abnormal

growth/development, infertility, abnormal organ function and the induction of secondary malignancies (Tait, 1992).

### c.) **Surgery**

In the event of them developing a tumour a child may undergo surgery to remove the malignancy. After removal of the tumour the child would be likely to receive chemotherapy or radiotherapy in order to destroy any remaining malignant cells. In some cases, the size and position of the tumour may be such that it would be considered too dangerous to remove the tumour via surgery. Depending on the location of the tumour, surgery may result in permanent scarring or loss of a limb.

### 1.2.6 **Side-Effects of Treatments for Childhood Cancer**

The therapeutic modalities employed in the treatment of childhood cancer, whilst typically effective in treating the cancer, are also associated with significant potential side-effects, including:

**Table 2      Potential Side-Effects of Childhood Cancer Treatments**

Emotional Difficulties	Mood Disturbances
Cognitive & Neurological Deficits	Academic Difficulties
Behavioural Problems	Personality Changes
Fertility & Reproduction Difficulties	Physical Disfigurement
Endocrine Deficits	Fatigue
Hearing Loss	Hair Loss
Secondary Malignancies	Altered Body Image
Nutritional Deficits	Abnormal Hormone Reproduction
Pericarditis	Thyroid Dysfunction

(Cited in Alcoser & Rodgers, 2003; Eiser, 1998; Kazak, 1994; Selby & Bailey, 1996; Shapiro & Brack, 1994)

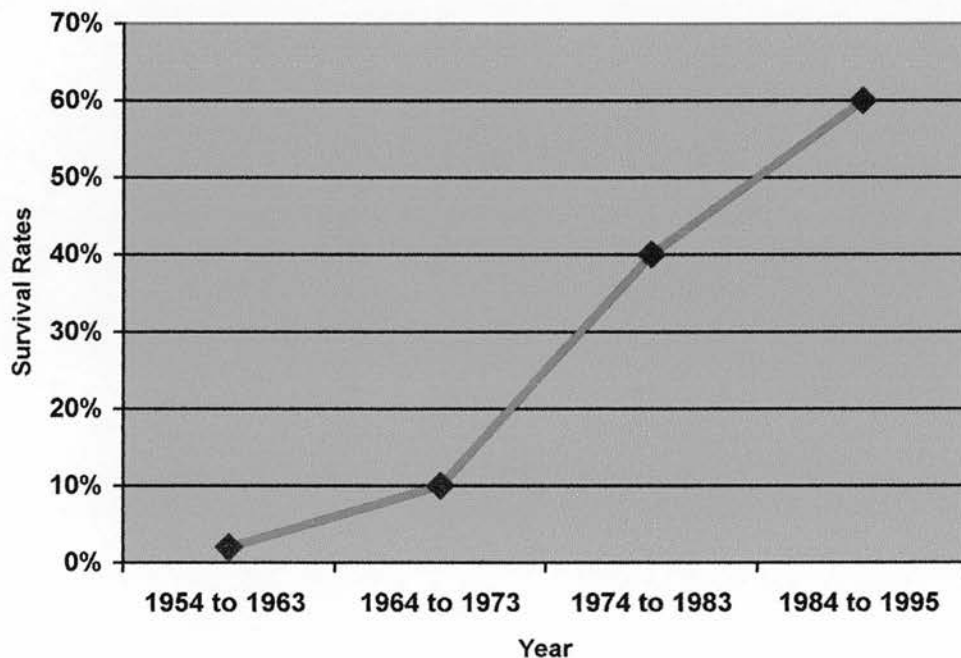
SIGN (2004) identified that survivors of childhood cancer may have growth impairment, cardiac problems, thyroid dysfunction, cognitive deficits and psychosocial difficulties. Cancer treatments can also affect the timing of puberty in children, particularly in females such as when early/precocious puberty is triggered by the treatment (Selby & Bailey, 1996). Friedman & Mulhern (1991) argued that all forms of childhood cancer treatments interfere with the individual's long-term quality of life. However Halperin, Constine, Tarbell & Kun (1999) and SIGN (2004) identified a number of factors that can potentially mediate the side-effects associated



with the treatment of childhood cancer, including: i.) tumour factors (i.e. size, location, type of tumour and tumour sensitivity), ii.) treatment factors (i.e. type, dose and combination of treatments delivered) and iii.) patient factors (i.e. age, developmental status and pre-existing conditions). In light of the potential short and long-term side-effects of childhood cancer, SIGN (2004) recommended the need for regular long-term monitoring of all adult survivors of childhood cancer.

### 1.3 THE CHANGING FACE OF CHILDHOOD CANCER

Historically, the diagnosis of childhood cancer was synonymous with death (Chao, Chen, Wang, Wu & Yeh, 2003), and is still invariably fatal if left untreated (Granowetter, 1994). However, with medical advances, centralisation of treatment and increased technology over the last two decades, the survival rate of childhood cancer has dramatically increased to over 60% (Varni, Katz, Colegrove & Dolgin, 1996). Consequently, childhood cancer has increasingly become viewed as a chronic rather than a terminal illness (Byrne, 1994). Figure 1 illustrates the increasing survival rates of Acute Lymphoblastic Leukaemia in children (Selby & Bailey, 1996);



**Figure 1 Long-Term Survival Rates of Acute Lymphoblastic Leukaemia (ALL) in Children/Adolescents**

However, as early as 1981 Koocher and O'Malley recognised that whilst there was an increasing survival rate of children with childhood cancer, there remained a high cost for the ill child and their families. Wang & Martinson (1996) also recognised that with the increasing survival rates there has been a significant change in the nature and types of stressors encountered and experienced by ill children and their families.

## **1.4 THE IMPACT OF CHILDHOOD CANCER**

### **1.4.1 Early Research into the Impact of Childhood Cancer**

Koocher & O'Malley (1981) argued that early research in this field was based on the underlying assumption that cancer was a fatal disease. Early research initially investigated the psychological effects of the loss of a child on bereaved families, the ill child's concept of the disease and their fear of death. As increasingly more children survived cancer, attention shifted towards the impact of childhood cancer on the ill child's parents and the parent-ill child dyad. There was an inherent tendency within earlier literature to consider the child almost in isolation from their families. However, as Vygotsky (1962) stated, a child does not exist in a vacuum. The British Psychological Society Briefing Paper, 'Working with Children with Medical Conditions', also acknowledged the effect which childhood illnesses can have on the family unit (BPS, 2003). Despite early recognition of the need to consider all members of the family in the child's cancer, research attention continued to predominantly focus on the ill child and their parents. This research emphasis was to the exclusion of other family members such as the healthy siblings of the child with cancer (Murray, 2000b). This lack of attention on healthy siblings resulted in a situation where healthy brothers and sisters of a child with cancer have been referred to as being 'emotionally overlooked' (Von Essen & Enskar, 2003) and as having 'unattended emotional needs' (Faulkner, Peace & O'Keefe, 1995). As a result of the historical tendency not to consider the impact of childhood cancer on healthy siblings, there is a certain degree of uncertainty/confusion regarding the potential impact of cancer on this population. Clearly this is an important area for future research, with significant implications for clinical practice.

### **1.4.2 The Impact of Childhood Cancer on the Ill Child**

Previous research suggests that children with cancer are at a significantly elevated risk of experiencing adjustment difficulties (Eiser, 1990). Research suggests that up to thirty percent of children with chronic illnesses, such as cancer, may experience long-term psychosocial difficulties (Melamed, 1991). This suggests that almost one third of children with cancer not only have to contend with the difficulties associated with the diagnosis and treatment, but they also have to attempt to manage its long-term psychosocial impact. Van Dongen-Melman & Sanders-Woudstra (1986)

emphasised how the potential life-threatening nature of cancer can be a major challenge for the ill child/adolescent and their families. Uncertainty regarding the future may be particularly difficult during adolescence, where deindividuation is one of the major developmental tasks of the period. Adolescence is a time when multiple physical changes occur and the adolescent has to attempt to manage these changes in as adaptive a way as possible. For an adolescent with cancer, the physical sequelae of the treatment approach may produce dramatic changes in their appearance. Their changing body image and their perceptions of how others perceive them may pose a major threat to their self-esteem and sense of worth.

Anxiety and phobias (especially in relation to medical procedures) are particularly prevalent amongst children with cancer, as is non-adherence (D'Angelo, 1992). Lansky, List & Ritter-Stern (1986) interviewed thirty-nine adolescent survivors of childhood cancer five to ten years post-diagnosis. They identified that, compared to normative data, the adolescent survivors of childhood cancer were at significantly elevated risks of experiencing: depression, alcoholism, suicidal ideations, behavioural problems, academic difficulties, financial difficulties and sibling difficulties. Previous research has also suggested that survivors of childhood cancer can experience: post-traumatic stress disorder, adjustment difficulties, hypochondriasis, low self-esteem and poor body image (Ferrari, 1984; Zebrack, Zeltzer, Whitton, Mertens, Robison, Odom & Berkow, 2002).

Whilst the research outlined above suggests that after a child/adolescent has been diagnosed with cancer they are likely to experience a number of difficulties, Koocher & O'Malley (1981) challenged the assumption that all children/adolescents will automatically experience such difficulties. Interviewing one hundred and seventeen survivors of childhood cancer, they concluded that the majority of individuals exhibited no/minimal psychological adjustment difficulties as a consequence of their diagnosis of cancer. In their research on the psychosocial adjustment of thirty-one five year survivors of childhood cancer, Friedman & Mulhern (1991) proposed that the short-term and long-term impact of cancer on children and adolescents are mediated by a number of factors including: age, gender, developmental level, family

support, early experience, severity of the disease, aggressiveness of treatment and time since treatment completion.

### **1.4.3 The Impact of Childhood Cancer on Parents**

Whilst some parents appear to be able to effectively adapt to their child's illness, others experience significant psychological and adjustment difficulties as a consequence of the diagnosis. Medical advances are such that increasingly parents are finding themselves in a state of 'limbo', distressed at their child's diagnosis, yet uncertain what the future holds. One of the primary functions of the parenting role is to protect their child from harm. However, childhood cancer strongly challenges the parental ability to protect, care for and nurture the child. Whilst the child is in hospital the parent may become increasingly aware that there has been a shift in the care of the child, from themselves to the health professionals (Koocher & O'Malley, 1981), producing an assault on a parent's identity (Futterman & Hoffman, 1977).

Sloper (1996) studied one hundred and thirty-three families of children with cancer and found significant proportions of both mothers and fathers to be experiencing a marked level of emotional distress. The diagnosis of cancer was also found to be associated with marked deleterious effects on parental employment and their financial status. Kupst & Schulman (1988) argued that emotional difficulties experienced by parents of children with cancer, exist not only during the course of the treatment, but for a considerable length of time post-treatment. Likewise, the period during the termination of therapy after a successful intervention may be an additional time of extreme anxiety for parents, particularly in terms of their uncertainty regarding the future (Friedman & Mulhern, 1991). Research suggests that the parental experience of childhood cancer is likely to be mediated by a number of factors, including; gender/age of the parent, age of the child, level of parental education, socio-economic status, parental personality type, previous parental experience of illness, parental/familial premorbid psychological functioning and religious affiliation (Eiser, 1990; Hoekstra-Weebers, Jaspers, Kamps & Klip, 1999).

## 1.5 THE SIBLING BOND

Siblings share a unique reciprocal bond (Williams, Lorenzo & Borja, 1993). The sibling relationship is one of the most enduring and life-long relationships that an individual is likely to have (Mancuso, Bishop, Blakeney, Robert & Gaa, 2003) and can be viewed as the precursor and testing ground for future relationships. Dunn, Deater-Deckard & Pickering (1999) emphasised the way in which sibling relationships are emotionally powerful and characterised by frequent and uninhibited interactions during early/middle childhood. The sibling relationship has been found to be of significant developmental importance, in terms of the individuals' cognitive, social and moral development (Boer & Dunn, 1992). In times of parental absence siblings can often act as a source of attachment for one another. For example, Dunn's (1993) research explored how siblings, as young as four years, were used by their younger siblings as a source of attachment security. Employing their older siblings as a secure base enabled the younger children to explore new and strange situations. From an early age children's/adolescent's relationships with their siblings teach them important skills in negotiation and conflict resolution, which are of fundamental importance in all their future interpersonal relationships (Azmitia & Hesser, 1993).

Significant associations have been found between the sibling relationship and children's functioning, including: anti-social and aggressive behaviour (Bank, Patterson & Reid, 1996; Boer & Dunn, 1992), socio-cognitive development (Dunn, Brown, Slomkowski, Tetra & Youngblade, 1991), children's resilience to marital disharmony (Dunn, Slomkowski & Beardsall, 1994), co-operative fantasy play (Dunn, 1988), self-concept and social skill development (Verte, Roeyers & Buysse, 2003). The longitudinal development of sibling relationships have been found to be influenced by direct and indirect factors, such as individual sibling characteristics (i.e. age and gender mix), family characteristics (i.e. marital satisfaction, financial situation and level of communication), parental characteristics (i.e. parental age and psychological difficulties), parenting strategies (i.e. differential parenting styles) and socio-economic factors (Stoneman & Berman, 1993).



Given the significance and importance of the sibling bond, it is highly likely that the diagnosis of childhood cancer will pose a major challenge to the sibling relationship (Byrne, 1994; Sloper & While, 1996). Post-diagnosis the sibling relationship is likely to be characterised by reduced opportunities for social interaction (due to frequent hospitalisations) and the typical tensions inherent within a normal sibling relationship (e.g. jealousy, protectiveness and friendship) may become increasingly exaggerated and complicated (Breyer, Kunin, Kalish & Patenaude, 1993; Hollidge, 2001).

## **1.6 IMPACT OF CHILDHOOD CANCER ON SIBLINGS**

Healthy siblings of children with cancer are less well adjusted than their ill sibling (Bendor, 1990), are significantly less likely to have their emotional needs addressed than the needs of the rest of the family (Dennis, 1995; Harding, 1996) and are a 'population at risk' (McKeever, 1983). However, whilst it is recognised that there are difficulties experienced by healthy siblings of children with cancer, the conclusions drawn from previous research have been inconsistent (Thompson, Curtner & O'Rear, 1994) and variable (Evans, Stevens, Cushway & Houghton, 1992; Sloper, 2000). Research into the impact of cancer on healthy siblings has also been defined as being overwhelmingly contradictory and confusing (Cuskelly, 1999; Dolgin & Phipps, 2000). The following section outlines the potential negative and positive effects that childhood cancer can have on healthy siblings.

### **1.6.1 Negative Impact of Childhood Cancer on Healthy Siblings**

Cairns, Clark, Smith & Lansky's (1979) study was amongst the first to study the impact of childhood cancer on healthy siblings. In their study of seventy-one children and adolescents (aged six to sixteen years), they found that siblings of children with cancer experienced significant levels of anxiety, depression and social isolation. They reported that parents typically under-recognised the difficulties experienced by healthy siblings. Strengths of this research are that it was amongst the first to directly involve the healthy siblings in the research, and it used standardised measures. However, the lack of a control group is a major limitation inherent within Cairns et al.'s findings. Research by Sloper & While (1996) identified that six months post-diagnosis twenty-five percent of siblings of children with cancer had experienced significantly increased difficulties. Whilst comparing the psychological functioning and adjustment of healthy siblings with the ill child with cancer, Evans et al. (1992) identified that healthy siblings actually exhibited greater psychological difficulties/adjustment problems than the ill child.

In her investigation into the impact of chronic illness, including childhood cancer, on healthy siblings, Sourkes (1987) reported a number of negative consequences that are often commonly experienced by the healthy sibling population, including:



- fear that they are to blame for their sibling's illness
- fear that they themselves will 'catch' the illness
- guilt that they managed to 'escape' the illness
- shame that their brother or sister is ill
- resentment that they are forced to engage in 'surrogate parent' tasks
- insecurity that their parents may be unable to protect *them* from similar harm

Examining the adjustment of one hundred and twenty-nine healthy siblings (aged four to sixteen years) of children with cancer, Cohen, Friedrich, Jaworski & Copeland (1994) identified that siblings in the cancer group were two standard deviations higher than the normative means for the internalising and externalising behaviour scales on the Child Behaviour Checklist (Achenbach, 1991). Whilst this study had a large sample size and employed standardised measures, their use of the normative data of the Child Behaviour Checklist, means that caution should be taken in drawing any specific conclusion from their research findings. For as Houtzager, Grootenhuis & Last (1999) identified employing normative data in such a way can lead to an over-estimate in the level of difficulties exhibited by healthy siblings of children with cancer. Sahler & Carpenter (1987) identified that healthy siblings of children with cancer experience marked sleep, eating, behavioural and academic difficulties. Whilst Sahler & Carpenter's study included a large number of participants and employed standardised measures the lack of a control group is a major limitation of the research. A research study of seventy-eight healthy siblings (aged ten to twenty years) of children with cancer found that compared to a control group forty percent of siblings of children with cancer experienced a mild post-traumatic stress reaction as a result of the diagnosis (Alderfer, Labay & Kazak, 2003). However, the control and cancer groups significantly differed on a number of demographic factors and thus caution should be taken in generalising these findings. One of the major challenges faced by a healthy sibling of a child with cancer is their need to adjust to the changes brought about by the cancer. Changes produced by the cancer can include: re-appointment of roles, increased responsibility and expectations and changes in the sibling's relationship with their ill sibling, their

parents and with their peers (Fleitas, 2000). As the attention of their parents increasingly focuses on the needs of their ill brother or sister, the healthy sibling may find their own needs becoming increasingly subordinated (Williams et al. 1993). If a healthy sibling is faced with their sibling being diagnosed with cancer, it is likely that all domains of their life will be significantly affected, including their attendance and performance at school (Taylor, 1980). Possible reasons why a healthy sibling may experience academic difficulties could include; emotional difficulties (e.g. anxiety or anger), deprivation of parental attention, concentration/attention difficulties, reduced opportunity/time to complete homework and interpersonal difficulties with school staff and peers.

If a healthy sibling spends a significant amount of time in a medical environment (e.g. when their ill sibling is in hospital) they may become increasingly preoccupied with their own health status. If separated from their parents, they may also experience an increasing sense of separation anxiety (Hersh, Wiener, Figuerana & Kunz, 1997). With the increased separation of family members healthy siblings of children with cancer may begin to assume parental type roles (such as caring for a younger sibling). This form of 'parentification' of the healthy sibling, may force them to take on roles/responsibilities which are beyond their developmental capabilities (Fleitas, 2000).

#### **1.6.2 Positive Impact of Childhood Cancer on Healthy Siblings**

Kramer (1981) was one of the first to recognise that whilst negative consequences (such as emotional stress/deprivation) could potentially be experienced by healthy siblings of children with cancer, positive consequences (such as increased levels of sensitivity, empathy and maturation) may also be experienced by this population. Though much research has suggested that healthy siblings typically experience difficulties as a consequence of their sibling's illness, this is not the case for all individuals, with many healthy siblings being at no increased risk of developing long-term psychological problems or psychopathology in adulthood (Van Dongen-Melman, De Groot, Hahlen & Verhulst, 1995). Sourkes & Proulx (2000) maintained that healthy siblings often developed new adaptive competencies and strategies to deal with the challenges of the illness. Murray (1998) reported a case study

investigating the experiences of one fourteen-year old healthy sibling of a child with cancer. He reported that with the diagnosis the healthy sibling identified that she had developed an increased empathy for others (for strangers as well as her own family and peers). The case study participant reported that she felt that she had matured as a result of the illness, and that her sibling's illness had also made her become more independent. Whilst the extent to which the findings of a single case-study can be generalised is limited, Murray's (1998) findings contrast with previous research which solely focused on the negative aspects of childhood cancer on healthy siblings.

Sargent, Sahler, Roghmann & Mulhern (1995) completed structured interviews with two hundred and fifty-four siblings of children with cancer. The interviews were designed to elicit the healthy siblings' feelings and thoughts about the effect that their siblings' illness had on them and their family. Positive consequences of the cancer reported in this research included closer family relationships and increased compassion. Kramer (1984) examined five healthy siblings' perceptions of what it was like for them to have a brother/sister with cancer. Healthy siblings of children with cancer reported that positive effects of their sibling's illnesses included increased sensitivity to and awareness of the needs of others and increased personal maturation. Unfortunately, the small sample size (i.e. five siblings) is a major limitation of this study, as is the lack of a control group and the reliance on unstandardised measures. Other positive consequences for a healthy sibling of a child with cancer which have been identified includes, enhanced social skills (Ferrari, 1984), increased altruism (Horowitz & Kazak, 1990) and increased sense of self-pride and self-efficacy (Iles, 1979).

## **1.7 IMPACT OF CHILDHOOD CANCER ON HEALTHY SIBLINGS' DEVELOPMENT**

Dunn (1988) characterised the sibling relationship as being of major developmental importance, with the sibling relationship playing a significant role in the cognitive, emotional, behaviour, moral and interpersonal development of children/adolescents. From an early age younger siblings are found to observe and imitate their older siblings (Azmitia & Hesser, 1993). According to Azmitia & Hesser, siblings play a key role in the cognitive development of their brothers/sisters. This has been found to be particularly the case in non-Western cultures, where the organisation of care-giving responsibilities is such that typically older siblings are often more influential than parents on the cognitive development of the younger siblings.

For Bibace & Walsh (1980) the development of a child's concept of illness follows Piaget's (1966) model of cognitive development. During the preoperational stage (i.e. approximately two to seven years) illness to a child is spatially and temporally remote. Illness is accounted for in terms of external events (e.g. where things are due to god or magic). As the child progresses to the concrete operational stage of cognitive development (i.e. approximately seven to eleven years), their ability to distinguish between the cause and manner of the illness increases. They increasingly become aware that the illness is contained within the body, however they view the cause as being external to the individual (e.g. 'my brother is ill because he/she swallowed/ate something bad'). At Piaget's final stage of cognitive development, the formal operational stage (i.e. approximately 11 years onwards) according to Bibace & Walsh (1980) the adolescent begins to be able to conceptualise the internal body as playing a role in the manifestation of the illness. They increasingly become aware that there are both psychological and physiological causes of illness. According to Bibace & Walsh, as an individual ages and there is an increase in their cognitive developmental level there will be an increase in their ability to conceptualise illness.

Bowlby (1969) reinforced the importance of the early relationship and attachment between the infant child and their primary caregiver. Lindsay & MacCarthy (1974)

undertook research that suggested that the healthy sibling group at highest risk of developmental difficulties due to their sibling's cancer is infants. They argued that if the necessary early bonding and attachment does not occur between the healthy infant sibling and their mother (i.e. possibly due to the parent's preoccupation with the ill child), then later cognitive, psychological, social, emotional and behavioural difficulties may be exhibited. Murray's (2000a) research also explored the effects of childhood cancer on the attachment of the healthy sibling. With the diagnosis of childhood cancer, the healthy sibling may become increasingly separated and isolated from their parents/carers, resulting in what Murray defined as a partial or complete deactivation of attachment behaviours. Ensuing attachment difficulties that may be exhibited by the healthy sibling could include difficulties such as anxiety, jealousy and interpersonal difficulties. Murray stated that the healthy siblings might engage in behaviours (such as anger, searching and blaming) as attempts at re-establishing the attachment bond.

A toddler who is too young to understand a verbal explanation for what is happening, may perceive parental preoccupation and lack of attention as a sign of rejection or as evidence that they are unloved/unlovable (Sourkes, 1987). If the toddler perceives the parent to be emotionally and physically distant, attachment issues may occur, as may a potential regression in the toddler's development (Pinkerton et al., 1994). D'Angelo (1992) explored how regression to earlier developmental levels can occur at any age in healthy siblings of children with cancer and does not necessarily occur solely in infancy/early childhood. The perception that their parents do not love them may persist throughout childhood (Langton, 2000). An older healthy sibling may understand why their parents are spending time with their ill sibling, however this understanding may be insufficient in preventing jealousy and resentment.

Fleitas (2000) emphasised the way in which young children's cognitive structures are relatively immature and are characterised by egocentric thoughts, feelings and behaviours. During early childhood a child's concept of illness is likely to be associated with personal experience and is typically global and concrete (Sourkes & Proulx, 2000). Langton (2000) stated that younger siblings may have difficulty in



understanding the aetiology of the illness, for example they may be fearful that they will somehow 'catch' the cancer. In cases where the healthy sibling is younger than the ill child they may compare themselves to their ill brother/sister and worry that, for example, 'when they are eight' they too will develop the disease. Only with the progression of time and age does the young child increasingly begin to develop an understanding of the wider context of illness, including, its causation and effects (Sourkes & Proulx, 2000). Younger children may not appreciate the severity and potential consequences of the cancer and therefore they may wonder what all the 'fuss' is about (Langton, 2000). Likewise, Pinkerton et al. (1994) emphasised the way in which it is unlikely that a young sibling of a child with cancer will be able to comprehend why their brother or sister has to have painful procedures and why for that matter their parents are allowing it to happen. Young children may have difficulty coming to terms with the realisation that their parents are unable to protect them from pain and harm as they are increasingly faced with the realisation that the world is not the safe place they once thought it to be.

Brannon & Feist (1997) emphasised the way in which children may perceive illness (either their own or others) to be a form of punishment for a real or imagined misbehaviour/misconduct. If a young child in early childhood thinks 'I wish my brother would go away' and then this is exactly what happens, in the young child's mind they may perceive themselves to be responsible and to blame for their sibling's cancer (Sourkes & Proulx, 2000). Pinkerton et al. (1994) explored the way in which a toddler may think that the treatment that their brother/sister is receiving is a punishment for something their sibling did wrong. If such thoughts persist then the young child is likely to experience emotional distress as a result.

With the transition from childhood to adolescence Piaget (1966) argued that there is a change in the individual's thinking, from the concrete operational stage to the formal operational stage. Piaget argued that as the individual moves from the concrete to the formal operational stage they will increasingly begin to think in abstract terms, think of the potential consequences and implications of different events and they will increasingly begin to be able to differentiate between the real

and the ideal. As Flavell (1977) stated, in adolescence, an individual is increasingly able to solve problems and think in a hypothetico-deductive way. Adolescents may hold the view that nothing can harm them (a belief which may be demonstrated by their engagement in risk-taking behaviour). Dacey & Kenny (1997) emphasised the way in which a sibling's illness can significantly challenge this view and can challenge the adolescent's egocentrism. When their brother/sister is diagnosed with cancer the adolescent may increasingly be faced with the realisation that they are not the centre of everyone's attention. Adolescence is a time when the individual thinks about and plans for the future. However, childhood cancer and the potential it has for being a terminal condition may negatively impact on the adolescent's view of the future and their ability to plan for it. With the adolescent's increased problem-solving and information processing abilities, healthy adolescent siblings of children with cancer are likely to have a better awareness and understanding of the effects and implications of the disease, than a younger child would. However, adolescents may experience more anxiety and fear as a result of their increased knowledge and awareness of the potentially life-threatening nature of their sibling's illness.

As a person reaches adolescence they increasingly become independent from their family, placing more emphasis and importance on peer relationships (Geldard & Geldard, 1999). It is a time usually associated with a weakening of family ties. The ability to be able to develop a sense of their own personal identity is of fundamental importance in adolescents' development. An adolescent's inability to establish a personal identity for themselves is likely to pose a significant threat to their sense of self-esteem (Koocher & O'Malley, 1981) and may increase the presence of psychological difficulties (Geldard & Geldard, 1999). If a healthy adolescent's brother/sister has been diagnosed with cancer it is highly likely that they may become (through choice or not) increasingly connected and attached to family members during the illness period. The lack of deindividuation from the family may negatively affect the adolescent's ability to deal with future difficulties in an effective and adaptive way.

## **1.8 RISK & RESILIENCE OF HEALTHY SIBLINGS OF CHILDREN WITH CANCER**

From a review of research investigating the impact of childhood cancer on healthy siblings it is apparent that there is not an overall consensus within the literature with regards to the impact of the disease on this population (Dolgin & Phipps, 2000). The review outlined above (section 1.6) suggests that whilst some healthy siblings experience marked difficulties as a consequence of their sibling's cancer, others appear able to effectively and positively adapt to the disease. This raises the question of why some healthy siblings are more able to adapt to childhood cancer than others. Melamed (1991) argued that a chronic illness per se is not a primary stressor that will automatically cause behavioural disturbances and emotional difficulties. Rather she argued that a number of factors mediate the impact of childhood cancer on healthy siblings including:

- illness characteristics
- characteristics of the healthy sibling
- family characteristics
- parental characteristics
- social characteristics

The following section explores the way in which the above characteristics can impact on and mediate the experiences of a healthy sibling of a child with cancer.

### **1.8.1 Illness Characteristics Related to the Risk or Resilience of Healthy Siblings of Children with Cancer**

It has been suggested that characteristics related to the ill sibling's cancer (such as type, severity, onset, duration of the illness and degree of incapacitation) may be related to the healthy sibling's risk or resilience to the illness (Brown, Kaslow, Madan-Swain, Doepke, Sexson & Hill, 1993; Kazak & Nachman, 1991; Sloper & While, 1996). More severe, more incapacitating and lengthier illnesses typically increase the risk of the healthy sibling exhibiting behavioural and psychological



difficulties (Barbarin, Sargent, Sahler & Carpenter, 1995). Upchurch (1997) argued that the nature of the family's communication and relationships with the health professions caring for the ill child can be a factor that protects or perpetuates the difficulties experienced by the healthy sibling. Likewise a further factor which was found to protect against or perpetuate healthy siblings' difficulties is the amount of time since their sibling was first diagnosed. Cohen (1985) argued that the longer the time since the ill child was diagnosed the better the outcome is for the healthy brother/sister. However, Pless & Nolan (1991) and Skidmore (1996) maintained that illness variables were not perpetuating or protective factors for the healthy sibling's adjustment.

### **1.8.2 Healthy Sibling's Individual Characteristics Related to their Risk or Resilience**

Von Essen & Enskar (2003) identified that healthy siblings aged between six and eleven years experienced the most marked difficulties as a consequence of their sibling's cancer. The most significant protective factors for healthy sibling difficulties were; a.) if the healthy sibling was over thirteen years and b.) if the healthy sibling was the first born in the family. Meanwhile Skidmore (1996) concluded that younger children tended to be better adjusted than adolescents. Barbarin et al. (1995), in contrast, argued that the age and gender of the healthy sibling were not significantly related to their adjustment. Other individual characteristics associated with the presence/absence of difficulties experienced healthy siblings, includes:

- premorbid psychological and behavioural functioning of the healthy sibling (Houtzager et al. 1999)
- the personality type of the healthy sibling (D'Angelo, 1992)
- level of healthy sibling self-esteem (Rutter, 1987)
- healthy sibling's motivational levels, coping resources, temperament and level of adaptive behaviour functioning (Brown et al. 1993)
- healthy sibling's appraisal of their situation (Brett & Davies, 1988)
- the healthy sibling's developmental level and cognitive style (Kazak & Nachman, 1991)

### **1.8.3 Family Characteristics Related to the Risk or Resilience of Healthy Siblings of Children with Cancer**

Koocher & O'Malley (1981) and Thompson et al. (1994) identified that healthy siblings from a lower socio-economic status are significantly more likely to experience adjustment difficulties to cancer than are healthy siblings from a higher socio-economic status family. Koocher & O'Malley (1981) argued that a lack of family communication may exacerbate healthy siblings' difficulties. Healthy siblings from families where the expression of emotions are not encouraged are found to experience more significant difficulties adapting to their sibling's cancer than in families where the free expression of emotions is positively encouraged (Koch, 1985). Fife, Norton & Groom (1987), Sahler, Roghmann, Mulhern, Carpenter, Sargent, Copeland, Barbarin, Zeltzer & Dolgin (1994) and Sourkes & Proulx (2000) stated that the presence or absence of other significant family life events (such as unemployment, bereavements, financial difficulties and geographical relocations) was a further factor that impacted upon healthy siblings' adjustment. The presence of chronic diseases in the family other than the child with cancer has found to be a significant factor that exacerbates the difficulties experienced by healthy siblings of children with cancer (Van Dongen-Melman et al., 1995). Further family characteristics related to whether or not the healthy sibling may experience difficulties are illustrated in the Table 3:

**Table 3 Family Characteristics Related to Risk or Resilience of Healthy Siblings of Children with Cancer**

Degree of Marital Satisfaction	Family Size
Parenting Style	Family's Prior Experience with Illness
Spirituality & Religiosity	Family Cohesion
Family Adaptability	Pre-Morbid Functioning of the Family
Cultural Background	Financial Status

(Cited in; Cadman, Boyle & Offord, 1988; Cohen et al. 1994; Iles, 1979; McKeever, 1983; Sloper & While, 1996; Sourkes & Proulx, 2000; Thompson et al., 1994; Upchurch, 1997).

### **1.8.4 Parental Characteristics Related to the Risk or Resilience of Healthy Siblings of Children with Cancer**

Within the general child literature a reciprocal relationship has been found between the parent's and the child's depressive symptomatology (Hammen, Gordon,

Jaenickie, Adrian, Burge & Hiroto, 1987). According to Beck (1967) when an individual is depressed they have a negative perception of themselves, their future and the world around them. The cognitive distortions, which Beck claimed were central to the causation and perpetuation of depression, are likely to not only produce negative and distorted views of the depressed individual but also of those around them (e.g. their children). Hammen et al. (1987) maintained that parental depression directly and indirectly influences the child's functioning and adjustment via both the parent's emotional behaviour and role dysfunction. Due to their own depression, sense of hopelessness and selective attention parents are less likely to provide their children with adequate and appropriate support, management and boundaries (Goodman & Brumley, 1990). They are also likely to be less tolerant of their child's non-compliant behaviours (Brody & Forehand, 1986).

Parental depression has been found to have a significant impact on the parent-child attachment relationship. The child's internalised working model of their primary attachment figure as being unresponsive and insensitive to their needs is likely to produce long-term difficulties for the child. Such difficulties may include insecure attachment, difficulties with emotional regulation, aggression, non-compliance, low self-esteem, sense of worthlessness and long-term difficulties in establishing and maintaining interpersonal relationships (Carr, 1999; Gelfand & Teti, 1990). Beardsall & Dunn (1992) discussed the difficulties in identifying the direction of the causal relationship between parental and child depression. For they emphasised that a child may become depressed as a result of their modelling of the parent's mood difficulties, whilst conversely the parent may become depressed as a result of their child's emotional/behavioural difficulties.

According to the genetics perspective the genetic bias and the resulting intergenerational transmission of depression may be viewed as being a further explanation for why depression is often exhibited by both the parent and child. For Bandura (1985) via the modelling and observation of their parental depressive behaviours (e.g. negative affect, unresponsiveness, hopelessness and criticism), the child may increasingly begin to adopt and internalise their parent's unfavourable

view of them and they may become increasingly susceptible to their parent's difficulties. Resulting in the child experiencing both behavioural and emotional difficulties as a way of dealing with the problems they are experiencing within the family context.

Parents of children diagnosed with childhood cancer have been found to be at a significantly elevated risk of developing psychological difficulties (such as depression) relative to a control group (Maguire, 1983). Parental difficulties have been found to be a significant factor that perpetuates difficulties experienced by the healthy siblings of children with cancer (Brown et al. 1993; Cohen, 1985). Terzo (1999) reported that parental health status and efficacy of parental coping strategies were significant factors which were predictive of whether a healthy sibling of a child with cancer would experience difficulties as a consequence of the illness. Whilst it is recognised and understandable that a parent of a child with cancer would be likely to experience their own psychological difficulties (such as depression), the extent to which such difficulties impact upon healthy children in the family remains somewhat unclear.

#### **1.8.5 Social Characteristics Related to the Risk or Resilience of Healthy Siblings of Children with Cancer**

Availability and access to resources and stable relationships with other adults in the local community have been identified as being related to the healthy sibling's resilience to their brother's/sister's illness (Rutter, 1987). Lack of social support has been identified as a further risk factor for perpetuating the difficulties and problems experienced by healthy siblings of children with cancer (Cohen, 1985; Sourkes & Proulx, 2000). Other social characteristics related to healthy sibling's risk/resilience to cancer, includes, interpersonal skills and peer functioning (Brown et al. 1993), school support and functioning (D'Angelo, 1992), kinship networks (Upchurch, 1997), extent of external social system (Sloper & While, 1996) and social isolation of healthy sibling (Hollidge, 2001).

### 1.8.6 Summary of the Risk & Resilience Factors for Healthy Siblings of Children with Cancer

Williams (1997) undertook a comprehensive review of the literature regarding healthy siblings of children with chronic illness (including cancer). From her review she concluded that the following were the most significant factors related to a healthy sibling's risk/ resilience to their brother's/sister's illness:

**Table 4 Predictors of Positive & Negative Adjustment in Healthy Siblings of Children with Cancer**

Predictors of Positive Adjustment	Predictors of Negative Adjustment
Good Parental Adjustment and Absence of Maternal Depression	Parental Depression
Good Marital Adjustment	Marital Difficulties
Good Social & Community Support	Presence of High Family Stress
Access to Family Resources	Absence of Family Expressiveness
Effective Family Communication and Problem-Solving Abilities	Lack of Family Cohesion
High Maternal Support	Time Since Diagnosis
High Sibling Self-Esteem	Pre-Diagnosis Sibling Difficulties

(Taken from Williams, 1997).

Based on the evidence discussed above, it would appear that there is a complex interaction between a myriad of different factors that impact on whether a healthy sibling will or will not experience psychosocial adjustment difficulties as a result of their sibling's cancer (Cohen et al. 1994; Sourkes & Proulx, 2000; Varni & Wallander, 1998).



## **1.9 AWARENESS REGARDING THE IMPACT OF CHILDHOOD CANCER ON HEALTHY SIBLINGS**

Whilst it is now recognised that the difficulties of a healthy sibling of a child with cancer may be manifested in psychological and behavioural problems (Gomez, 1998), one of the major difficulties in exploring the impact of cancer on healthy siblings is the often inaccurate accounts provided by the healthy siblings, their parents and/or health professionals. The following section explores why there is a lack of awareness regarding the impact of childhood cancer on healthy siblings.

### **1.9.1 Healthy Siblings' Awareness of the Effects of Childhood Cancer**

Selby & Bailey (1996) identified that healthy siblings themselves have a tendency to under-report the difficulties that they are experiencing as a consequence of their sibling's illness. Reasons for this under-reporting includes: their sense of isolation, their awareness that parental attention is concentrated on their ill sibling (Cairns et al. 1979; Selby & Bailey, 1996) and their denial of the existence of difficulties in an attempt to protect their parents/families (Sharpe & Rossiter, 2002; Sourkes & Proulx, 2000). Healthy siblings may not know why they are feeling the way they do, they may not attribute their difficulties to their sibling's illness or they may believe that their own needs are secondary to the needs of their ill brother or sister. As was discussed in section 1.7, depending on their developmental stage healthy siblings may perceive themselves to be to blame for their sibling's illness. If this is the case then healthy siblings may convince themselves that they 'deserve' the difficulties they are experiencing. Thus they may not tell their parents or others about these difficulties.

### **1.9.2 Parental Awareness of the Effects of Childhood Cancer on Healthy Siblings**

Cairns et al. (1979) reported research which indicated that whilst a significant proportion of healthy siblings of children with cancer experienced difficulties as a result of their sibling's illness, parents typically did not tend to recognise these needs. Menke (1987) compared parents and healthy siblings with regards to their

perceptions about how the healthy sibling's functioning. He found that parents typically under-estimated the difficulties experienced by their healthy children, with twenty-five percent of parents reporting their healthy children as experiencing no difficulties, compared to only eleven percent of the siblings themselves identifying that they were not experiencing any difficulties. Craft & Craft (1989) also found that parents typically under-estimate the impact of illness on healthy siblings of children with cancer and suggested that this may be due to reduced parental sensitivity to cues, reduced family communication and increased periods of parent/healthy sibling separation. Carpenter & Sahler (1991) stated that parents' under-estimation of the impact of childhood cancer on healthy siblings may lead to the needs of this population remaining unmet. Zeltzer, Dolgin, Sahler, Roghmann, Barbarin, Carpenter, Copeland, Mulhern & Sargent (1996) argued that compared to a control group healthy siblings of children with cancer are significantly less likely to be taken to the doctor by their parent. From their research, Zeltzer et al. (1996) concluded that parental under-reporting of the health difficulties of healthy siblings was a common characteristic in families of children with cancer.

In contrast to Menke's (1987) research which found that parents typically under-reported healthy siblings' difficulties, Sharpe & Rossiter (2002) maintained that parents tended to report that the healthy sibling had significantly more difficulties than was identified by the siblings themselves. Similarly, Taylor, Fuggle & Charman (2001) identified that mothers were significantly more likely to report the siblings as having difficulties/negative perceptions than was reported by the healthy siblings themselves. The extent that these findings can be generalised is limited due to the study's reliance on normative data and a lack of a control group. Even when parents and healthy sibling agree on the fact that the healthy child is experiencing some difficulties, they tend to disagree about the source of difficulty for the healthy sibling. For example, Breyer et al (1993) reported that whilst healthy siblings perceived general worry regarding their ill sibling to be the major difficulty for them, parents perceived loss of parental time and attention to be the greatest source of difficulty for the healthy sibling. Breyer et al. argued that parents might have difficulty in correctly recognising the impact of the cancer on their healthy children



due to a parental under-estimation of the importance of the sibling relationship. Likewise, at a time when they themselves are experiencing significantly heightened emotions, parents may have difficulty in acknowledging the distress experienced by their healthy child. Conrad & Hammen (1989) stated parents' own psychological functioning was a significant factor associated with their capacity to recognise the needs of their healthy children. They argued that parents who were 'psychologically well' typically under-estimated the effect of cancer on the healthy siblings, whilst parents who were not 'psychologically well' were more likely to over-estimate the impact of illness on healthy siblings.

### **1.9.3 Health Professionals' Awareness of the Effects of Childhood Cancer on Healthy Siblings**

Due to the severity of the illness and the ensuing focus on the ill child, health professionals may be unaware of the effect of childhood cancer on healthy siblings (Eiser & Havermans; 1992, Sloper 2000). Hersh et al. (1997) identified that unless a crisis situation emerges with the healthy sibling, the needs of the sibling are typically not brought to the attention of, or considered by, health professionals working with the family.

### **1.9.4 Summary of the Lack of Awareness of the Effects of Childhood Cancer on Healthy Siblings**

One of the major limitations of early research into the impact of cancer on healthy siblings is the tendency to use only parental reports as a source of information regarding the adjustment of the healthy sibling (Baggot, Kelly, Fochtman & Foley, 2002). This is despite the fact that, as Phares, Compas & Howell (1989) emphasised, children's/adolescent's self-reports reflect a compilation of behaviours across different settings, whereas parental reports are typically based on their impression of the child/adolescent in one particular setting (e.g. home). Research by Walker (1988) challenged the efficacy of using parental reports when she argued that there could be as high as forty-four percent disagreement between parents and healthy siblings on reports of the sibling's functioning and adjustment. Terzo (1999) identified that reliance on parental reports may produce data that lacks sensitivity to

the actual experiences of the healthy child. The design of the present research aimed to overcome the tendency to use only parents as a source of information regarding the functioning of the healthy sibling. It is hoped that by including parents and healthy siblings a more accurate and balanced understanding regarding the impact of childhood cancer on the healthy siblings will be achieved.

## **1.10 METHODOLOGICAL ISSUES OF PREVIOUS RESEARCH**

As identified in the preceding section (section 1.9), one of the methodological constraints of previous studies into the effects of childhood cancer on healthy siblings is the over-reliance on parental reports and the under-reliance on the healthy sibling's reports of their functioning and experiences (Sloper, 2000). The methodological weaknesses inherent within previous research have resulted in conflicting and inconsistent findings (Kazak & Nachman, 1991). Lehna (1998) argued that one reason for the inconsistent findings in the research could be a result of the diverse research methodologies that are used across different studies. The range of methodological weaknesses inherent within previous research makes it somewhat difficult to compare and contrast the results of different research studies. The main methodological weaknesses of previous research explored below are:

- a.) the characteristics of participants included in research studies
- b.) the lack of comparison control groups
- c.) difficulties associated with the types of assessments/measures previously employed.

### **1.10.1 Characteristics of Participants**

Kazak (1994) emphasised that the broad age ranges of healthy siblings included in previous research causes difficulties in the extent to which conclusions may be drawn from the research findings. As was discussed in section 1.7 there are significant developmental differences in children/adolescents' conceptualisation of illness therefore including a sample population with a wide range of ages may confound the data obtained. The actual incidence of childhood cancer is relatively low (see section 1.2.2) and consequently the inclusion of different aged children and adolescents may be a by-product of the simultaneous need for statistical power with the relatively low prevalence of cancer in children (Williams, 1997). The low prevalence of childhood cancers may also be the reason why previous research has tended to involve a relatively small number of participants, resulting in a limitation

in the extent to which the findings of previous research can be generalised to the population as a whole. The low prevalence rate and participant population may also account for why, as Bluebond-Langer (1996) stated, previous research typically included healthy siblings of children with a wide range of different types of cancer and at different disease stages.

### **1.10.2 Lack of a Control Group**

As Breakwell, Hammond & Fife-Schaw (1995) emphasised, only by the inclusion of a control group can researchers be certain of the attribution of causality of observed findings. However, most of the previous studies investigating the impact of childhood cancer on healthy siblings have not used an appropriate control group (e.g. as in Cohen et al. 1994, Barbarin et al. 1995; Evans et al. 1992; Koch, 1985). Instead of using a control group, previous research has often compared the assessment/measurement results of healthy siblings of children with cancer with normative sample data. As Howe (1993) and Sharpe & Rossiter (2002) stated, the over-reliance on normative data may result in a misrepresentation of the difficulties experienced by healthy siblings. Gallo, Breitmayer, Knafl & Zoeller (1991) further criticised the over-reliance on normative data when they argued that “Even though normative data is considered representative, many families with a child with a chronic illness may not be representative because many illnesses are not distributed evenly throughout the child population.” (Pg. 26)

Previous research has commonly employed the ill siblings with cancer as a control group for the healthy sibling sample. The extent to which it can be argued that a group of children with cancer can be viewed as being representative of the ‘normal’ population with whom the healthy sibling population can be compared is clearly suspect. Without an adequate control group it would be difficult to identify the extent to which the data obtained from healthy siblings of children with cancer are characteristic of their population or were experienced by all children/adolescents.

### **1.10.3 Assessments & Measures Employed**

A further weakness of previous research into the impact of childhood cancer on healthy siblings is the type of assessments/measures that have been employed. There is significant variation in the types of methodologies used, including both standardised and unstandardised measures (Bluebond-Langer, 1996). The employment of unstandardised measures makes it difficult to make comparisons between the findings of different research studies (Havermans & Eiser, 1994; Stallard, Mastroyanopolou, Lewis & Lenton, 1997). Some previous research studies have also employed adult measures, which have not been standardised for use with children/adolescents (Gardner, 1998). This has resulted in a situation where developmentally inappropriate, and potentially invalid and unreliable measures have been administered to participants. Due to time restrictions and ethical issues in involving children in research, previous research has also tended to rely on parental reports, rather than asking the siblings themselves about their experiences. This reliance on parental reports is particularly problematic in light of the fact that, as explored in section 1.9.2, parents often under/over-estimate the impact of the cancer on their healthy children (Sloper, 1996).

### **1.10.4 Further Methodological Weaknesses**

The following additional methodological weaknesses have been identified as limiting the reliability and validity of previous research into the impact of childhood cancer on healthy siblings:

- Varying inclusion/exclusion criteria (Bluebond-Langer, 1996)
- Over-reliance on retrospective & anecdotal information (with data being collected either after the child with cancer has died or after a long-time post-diagnosis) (Byrne, 1994)
- Lack of longitudinal follow-up data (Houtzager et al. 1999)
- Over-reliance on single-subject case studies (Lobato, Faust & Spirito, 1988)

## **1.11 AIMS & HYPOTHESES OF PRESENT STUDY**

### **1.11.1 Aims**

The aim of the present study is to examine the effect of childhood cancer on healthy siblings. As was discussed in Section 1.10 the methodological weaknesses of much of the previous research in childhood cancer has led to inconsistent research findings with regards to the impact of the illness on healthy siblings. Section 1.8.4 discussed the way in which parental psychopathology has been found to have a significant impact on the behaviour and emotional well-being of children/adolescents within the general population. However this is something of an under-researched area within the childhood cancer literature. Thus the present study aimed to examine the extent to which parental mood can impact on the functioning of healthy siblings of children with cancer. Earlier research literature suggested that there tends to be a discrepancy in terms of parents'/healthy siblings' perceptions regarding the impact of childhood cancer on healthy siblings (Walker, 1988). The present study aimed to examine the extent to which there is agreement/disagreement between parental and sibling perceptions of the impact of childhood cancer on healthy siblings. It is proposed that this is a relevant area for future research, particularly in terms of the impact which parental understanding can have on the adjustment of their healthy children. By involving the healthy siblings themselves, by employing age-appropriate standardised measures and by comparing them with a matched control group the present research aimed to overcome some of the methodological weaknesses of previous research in this area.

### 1.11.2 Hypotheses

#### **a.) Hypothesis One**

*Healthy siblings of children with cancer will exhibit more psychological and behavioural difficulties than children/adolescents in a control group*

Most previous research in the area of childhood cancer has examined the impact of the illness on parents and the ill child, with little attention being paid to the impact on healthy siblings. Healthy siblings of children with cancer continue to be an under-researched and ‘forgotten’ population. Whilst some research studies have found healthy siblings of children with cancer to be at an elevated risk of experiencing difficulties, other research has found the population to be at a no greater risk of developing difficulties than the general population (see Section 1.6). Unfortunately, previous research in this area has been both variable and inconsistent, typically relying on unstandardised measures, normative data and upon parental reports. This has produced inconclusive findings that are limited in the extent to which they can be generalised to the population as a whole. The lack of control groups with whom to compare the healthy siblings to, have been a major limiting factor in previous research. By developing a more rigorous and methodologically sound research design the present study explores the way in which healthy siblings can potentially be effected, both psychologically and behaviourally, as a result of their brother’s/sister’s cancer. Hypothesis one proposes healthy siblings of children with cancer will exhibit more psychological and behavioural difficulties than children/adolescents in a control group.

#### **b.) Hypothesis Two**

*Parents and healthy siblings will disagree regarding the impact of childhood cancer on healthy siblings*

Early research into the impact of childhood cancer on healthy siblings typically relied on parental reports. Whilst parents are clearly an important source of information regarding the impact of the illness on the healthy siblings, there are



marked inconsistencies within the research regarding the extent to which parents and healthy siblings agree regarding the impact of childhood cancer on the healthy children (Walker, 1988). For example, whilst Sharpe & Rossiter (2002) hypothesised that parents typically over-estimate the impact on healthy siblings, Menke (1987) argued that parents often under-estimate the extent to which cancer negatively impacts on the healthy children/adolescent. Recognising the significant impact that childhood cancer can have on the parents themselves (such as fear, anxiety, depression, low self-esteem and reduced coping abilities) and their increased focus on the needs of the ill child, the second hypothesis proposes that parents and healthy siblings will disagree regarding the impact of childhood cancer on healthy siblings.

### **c.) Hypothesis Three**

*Parents of healthy siblings in the oncology group will be significantly more depressed than parents of healthy siblings in the control group*

Sloper's (1996) research found that significant proportions of parents of children with cancer experienced marked levels of psychological distress as a result of their child's cancer. As was discussed in section 1.4.3 whilst some parents are able to adjust to their child's/adolescent's diagnosis of cancer, other parents experience significant psychological distress as a result of the diagnosis. Previous research investigating the psychological impact of childhood cancer on parents have been limited in two main ways, their use of unstandardised measures and their lack of a control group. By employing an extensively standardised and widely used assessment of depressive symptomatology in adults and the use of a control group enables the present study to overcome the methodological weaknesses of the prior research. The third hypothesis proposes that parents in the oncology group will be significantly more depressed than parents whose child/adolescent has not been diagnosed with a chronic illness.

**d.) Hypothesis Four**

*The psychological and behavioural functioning of healthy siblings of children with cancer will be significant variables in predicting the psychological functioning of their parents*

General research into the impact of parental mental health functioning suggests that children and adolescents of parents who are depressed are at a significantly increased risk of developing psychological difficulties themselves. Whilst it has been recognised that childhood cancer can increase the risk of parents developing depression, little research attention has focused on the extent to which the psychological and behavioural functioning of healthy siblings of children with cancer is predictive of parental depressive symptomatology. The fourth hypothesis of this study therefore predicts that the psychological and behavioural functioning of healthy siblings of children with cancer will be significant variables in predicting the psychological functioning of their parents.

## **CHAPTER TWO - METHOD**

## **2.1 DESIGN**

An independent-group design was employed to compare the data from a participant group of healthy siblings of children with cancer with a control group. Parents and healthy siblings of children/adolescents referred to the Paediatric Oncology Departments of NHS Lothian and NHS Tayside formed the oncology group. The control group was made up of children/adolescents and their parents from a primary and secondary school in the Tayside area.

## 2.2 PARTICIPANTS

Two groups of children/adolescents participated in this research study. A participant group of healthy siblings of children with cancer and a control group<sup>5</sup>. The oncology group was selected from two NHS Paediatric Oncology Departments and the control group was selected from a Primary and Secondary School in Scotland. Table 5 demonstrates the number of participants, in both the oncology group and the control group, who were invited to participate and who consented to participate.

**Table 5**      **Number of Participants in the Oncology & Control Groups**

	<b>Oncology Group</b>	<b>Control Group</b>
<b>Number of Participants Invited to Participate</b>	76 families Consisting of <b>103</b> Healthy Siblings	270 from a Primary School 360 from a Secondary School <b>630</b> Participants
<b>Number of Participants who Participated in the Research</b>	25 (from 18 families)	65 (from 65 families)

### 2.2.1 Inclusion/Exclusion Criteria

#### **Oncology Group-Inclusion/Exclusion Criteria**

Healthy siblings of children with cancer for the oncology group were included if they satisfied the following criteria;

#### **Inclusion Criteria**

- has a sibling with childhood cancer (the ill sibling can be of any age)<sup>6</sup>
- healthy siblings aged eight to seventeen years
- the healthy siblings were born before the diagnosis was made

<sup>5</sup> It was considered important to employ a control group as previous research has suggested that the frequency of difficulties experienced by healthy siblings of children with cancer may be over-emphasised in studies without a control group (Ferrari, 1984).

<sup>6</sup> Whilst some research has limited the inclusion criteria to one healthy sibling per family, in line with Barbarin et al. (1995) and Rowitz (1993), the present research has included all healthy siblings (who satisfy the inclusion/exclusion criteria) within the same family. For as Richman & Stocker (2003) identified there can be a differential impact of family events (such as childhood cancer) on different healthy siblings in the same family.

**Exclusion Criteria**

- families with more than one ill child
- parents or healthy siblings with a chronic illness/learning disability
- individuals/families whom medical staff viewed as being at risk of experiencing significant distress as a result of participating in the research
- families where the diagnosis has been made within the last six months
- bereaved families

**Control Group-Inclusion/Exclusion Criteria**

The participants were included in the control group if they satisfied the following criteria;

**Inclusion Criteria**

- children/adolescents aged eight to seventeen years
- has a healthy brother/sister of any age (i.e. younger or older to them)

**Exclusion Criteria**

- children/adolescents who have a chronic illness/learning disability
- children/adolescents whose sibling has a chronic illness or developmental disability
- individuals/families whom school staff viewed as being at risk of experiencing significant distress as a result of their participation in the research

## **2.3 SETTING**

### **2.3.1 Oncology Group**

Participants in the Oncology Group were selected from the Paediatric Oncology Departments of NHS Lothian and NHS Tayside. The Paediatric Oncology Department of NHS Lothian is based at the Royal Sick Children's Hospital, a specialist hospital in Edinburgh that serves children/adolescents within Lothian (Lothian's population is approximately 780 000 individuals) (NHS Lothian, 2001). The Paediatric Oncology Department of NHS Tayside is based at Ninewells Hospital, Dundee, a general medical hospital covering the entire population of Tayside (approximately 390 000 individuals) (NHS Tayside, 2003a). Both departments are multi-disciplinary teams consisting of consultant paediatricians, nursing staff, clinical psychologists, social workers, dieticians, pharmacists and play therapists.

### **2.3.2 Control Group**

Perth and Kinross Education Authority granted permission for the research to be undertaken in a Primary School and Secondary School within the geographical boundary of NHS Tayside. The Primary School has a population of 600 pupils and the Secondary School has a population of 1500 pupils.



## **2.4 ETHICAL CONSIDERATIONS**

A proposal for this research study was submitted to the Tayside Committee on Medical Research Ethics and the Lothian Paediatrics/Reproductive Medicine Research Ethics Committee. Ethical approval for the research to take place in Tayside was obtained in February 2004 and in April 2004 in Lothian. (Appendix One illustrates the letters confirming that ethical approval was obtained for this research study to take place). Approval from the Research & Development Departments of NHS Tayside and NHS Lothian was also obtained, as was approval from Perth & Kinross Education Authority.

In light of the nature of this research a number of potential ethical issues were considered prior to the undertaking of the research.

### **2.4.1 Participant Distress**

It was acknowledged that parents and children/adolescents, in both the control group and the participant group, might experience some degree of distress and upset as a result of their completion of the measures (i.e. due to the personal nature of some of the questions). Standardised measures, routinely employed with adults and children/adolescents, were used to reduce the risk of any individual experiencing unnecessary distress as a result of their participation in the research.

In order to protect the families of children with cancer from having to experience any further psychological distress it was agreed with medical staff that those families whom clinicians (of the Paediatric Oncology Services) viewed as being at potential risk by their participation in the research would not be invited to participate.

Participants were provided with contact details of individuals whom they could contact if they experienced distress or difficulties in their participation in the research. They were also offered the opportunity of psychological input from a member of the Clinical Child & Adolescent Psychology Department if they wished. In a situation where the healthy sibling was under twelve years of age it was agreed from the outset that the matter would be initially discussed with their parent, prior to

the child being offered psychological input. Offering the participants the opportunity to debrief after completing the measures was also aimed at reducing any potential difficulties and distress they may experience as a by-product of their participation in the research. The information sheets sent to individuals also advised them of their right to withdraw from the study at any time.

#### **2.4.2 Confidentiality**

All participants were allocated a code number for reasons of anonymity and confidentiality. The measures and data collected in this research were stored in a secure locked filing cabinet and information stored on a computer was password access only. In order to maintain and protect their confidentiality and anonymity, participants were not asked to provide any identifying information regarding themselves or their families. Consequently, it was not possible to identify, by name, those individuals who were experiencing a significant level of psychological distress, as measured by their completed measures. From the outset of the research it was recognised that this may lead to a situation where participants with severe difficulties remained untreated. Whilst this possibility was recognised the researchers considered it important to maintain the confidentiality/anonymity of participants as much as feasibly possible. The information sheets provided individuals with the contact details of the principal researcher, local adviser and Paediatric Oncology Department, whom they could contact should they experience distress whilst completing the questionnaires/measures. The information sheet also advised them not to complete the questionnaires/measures if they found them distressing.

#### **2.4.3 Role of School Staff**

It was acknowledged that it might be somewhat difficult for school staff to be able to identify whether a pupil has a sibling with a chronic illness. Rather than relying on school staff to address this issue with the pupils, a question in the demographic information sheet asked if any child/adolescent in their immediate family has a chronic illness or a learning disability. If a positive response were provided to this question the data from this family would not be included in the final analysis of the results. It was considered that this was an appropriate and feasible way of addressing whether or not a chronic illness/learning disability was present in the control group.

## 2.5 PROCEDURES

### 2.5.1 Oncology Group

Based on the inclusion/exclusion criteria, medical staff identified those participants whom they considered to be suitable potential candidates to participate in the research <sup>7</sup>. The medical staff of the Paediatric Oncology Departments of NHS Lothian and NHS Tayside provided the researcher with the name and addresses of these families. Any family whom medical staff considered could potentially experience significant undue distress/ trauma from their participation in the research was not invited to participate <sup>8</sup>. Packs regarding the research were sent to the identified families. These packs contained the following;

- an introduction letter from the Consultant and the Researcher informing the parents about the research <sup>9</sup>
- an information sheet for parents regarding the research
- an information sheet for children under twelve years
- an information sheet for adolescents over thirteen years
- a demographic questionnaire to be completed by parents
- a Beck Depression Inventory-II
- a Child Behaviour Checklist
- a Sibling Perception Questionnaire – Parent Version
- a Child Depression Inventory
- a Sibling Perception Questionnaire – Child/Adolescent Version
- stamped addressed envelopes

Appendix Two illustrates the letters sent to parents, Appendix Three contains copies of the information sheets, questionnaires/measures completed by parents are included

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<sup>7</sup> Whilst the participants in this study were not themselves the patients of the Consultant Paediatricians (the children with cancer were) permission was sought from medical staff for the families to participate in the research.

<sup>8</sup> In NHS Tayside a Specialist Paediatric Oncology Nurse and in NHS Lothian an Associate Specialist were responsible for identifying those families whom they considered to be suitable participants for the research.

<sup>9</sup> Copies of the letter and information sheets sent to parents and healthy siblings are illustrated in Appendix Two and Three.

in Appendix Four and Appendix Five illustrates copies of the questionnaires/measures completed by the healthy siblings.

The information sheets outlined the rationale for the research and advised individuals with regards to what was involved if they chose to participate in the research. If they consented to participate in the research individuals were requested to return the completed questionnaires in the stamped addressed envelope. The information sheet advised individuals that if they returned the completed measures it would be presumed that they had consented to participate in the research. They were provided with contact details for the researcher, the local adviser and the Paediatric Oncology Departments whom they could contact if they experienced distress as a result of their participation in the research or if they had any queries regarding the study.

### **2.5.2 Control Group**

Consent was sought from the local Education Authority for data to be collected from a Primary and Secondary School in the local area. The local Education Authority identified two schools who were willing to participate in the research. The researcher met with staff at both schools in order to provide them with further information regarding the research. Staff at the two schools were provided with packs to distribute to pupils aged between eight and seventeen years. These packs contained the following;

- an introduction letter outlining the research
- an information sheet for parents regarding the research
- an information sheet for children under twelve years
- an information sheet for adolescents over thirteen years
- a demographic questionnaire to be completed by parents
- the Beck Depression Inventory-II
- the Child Behaviour Checklist
- the Child Depression Inventory
- a stamped addressed envelope

The information sheet asked individuals in the control group to complete the measures and return them in the enclosed stamped addressed envelope. In order to protect the anonymity of the individuals in the control group they were not asked to provide any personal identifiable information. Individuals were advised that by returning the completed questionnaires, it would be assumed that they had given their informed consent to participate in the research. Individuals in the control group were provided with the contact details of the researcher whom they could contact if they had any questions regarding the research or if they became distressed as a result of their participation in the research.

## **2.6 MATERIALS & APPARATUS**

### **2.6.1 Information Sheets**

Information sheets for both the oncology and control groups outlined the rationale for the research and what would be involved if individuals consented to participate in the research. These information sheets also outlined issues of consent and the course of action that individuals should undertake if they became distressed as a result of the research (i.e. contacting Principal Researcher, the Local Adviser or the relevant Paediatric Oncology Department). In line with the requirements of the Tayside and Lothian Committees on Medical Research Ethics, separate age-appropriate information sheets were developed for children under twelve years and for adolescents over thirteen years. To ensure as many people as possible understood the information sheet, NHS Tayside's (2003b) Good Practice Guidelines for Developing Written Information for Patients was followed. These guidelines recommended that the readability scores for all written information given to individuals should be calculated using the Flesch Reading Ease Score computerised procedure. The readability for the information sheets included in this research was calculated (at above sixty percent) and thus it was identified that as defined by the guidelines for the Flesch Reading Ease the majority of individuals would be able to understand the information (NHS Tayside, 2003b).

### **2.6.2 Parent – Completed Measures**

Appendix Four illustrates copies of the parent completed questionnaires/measures.

#### **Demographic Questionnaire**

In order to obtain background demographic data, a questionnaire was designed for the purposes of the present study. The following information was obtained from the demographic questionnaire;

- age and gender of the healthy sibling
- relationship of adult completing the measures to the child/adolescent whom they are completing the measures for (e.g. mother, father, guardian etc.)
- marital status of parent
- parents' occupation

The National Statistics Socio-Economic Classification (NS-SEC) (2004) was used in order to classify the occupations of parents who participated in the study. The NS-SEC is the occupation-based classification system used by the government in official statistics and surveys since 2001. It is a measurement of employment relations and conditions of occupations that are viewed as being central to identifying socio-economic status in modern society. Occupations are divided into nine separate classifications. (Appendix Six illustrates the NS-SEC classifications).

The following additional demographic information was also collected from parents in the oncology group;

- age and gender of ill sibling
- diagnosis given to the ill sibling
- type of treatment given to the ill sibling
- time since diagnosis

#### **The Child Behaviour Checklist (Achenbach, 1991)**

The Child Behaviour Checklist is a standardised self-administered measure of parents' perceptions of the behavioural problems and social competencies exhibited by children/adolescents. The checklist was designed for children/adolescents aged four to eighteen years. The one hundred and eighteen behavioural items assess a wide range of behavioural difficulties, including internalising (made up of the withdrawal, somatic complaints and anxiety/depressed profiles) and externalising behaviours (made up of delinquent problems and aggressive behaviour profiles). The twenty social competence items measures the child's/adolescent's proficiency/competency in social activities, social relationships and school (Gallo et al. 1992).

Parents are required to rate each of the items on a three-point Likert Scale with each point on the scale representing a corresponding score; not true (0), somewhat true (1) and very true (2). Parents are asked to base their responses to the items on the healthy sibling's behaviour over the previous six months. The total raw scores for the behavioural problems and social competence items are converted to T-Scores.



The T-Scores provides classification of the child's/adolescent's functioning (e.g. within the normal, borderline or clinically significant range). The clinical range for the social competence scales is a T-Score of 30 to 33, whilst the clinical range for the behaviour problem scales is a T-Score of 60 to 63 (Achenbach, 1991). A clinically significant score on the behaviour problem scales is suggestive that the child/adolescent is exhibiting a significant level of behaviour problems, whilst a clinically significant score on the social competence scales is indicative that the child/adolescent is experiencing social and interpersonal difficulties. Achenbach (1991) argued that a discrepancy of ten points between the internalising and the externalising T-Scores was of clinical significance.

The Child Behaviour Checklist has been extensively statistically analysed using factor analysis and norms for different age groups/genders have been established (Edelbrock & Achenbach, 1980). High test-retest reliability ( $r = .87$  for social competence items and  $r = .89$  for behaviour problem items) and inter-parent agreement ( $r = .79$  for social competence items and  $r = .76$  for behaviour problem items) has been established for the Child Behaviour Checklist (Achenbach, 1991). The content validity of the Child Behaviour Checklist was demonstrated by its ability to significantly discriminate between demographically matched referred and non-referred children/adolescents (Achenbach, 1991). Verhulst, Achenbach, Althaus & Akkerhuis (1988) emphasised the validity of the checklist with a non-clinical population. The construct validity of the checklist, has found to be significantly correlated with the Connors Parent Questionnaire ( $r = .82$ ) and the Quay-Peterson Revised Behaviour Problem Checklist ( $r = .81$ ) (Achenbach & Edelbrock, 1978). As Houtzager et al. (1999) identified the Child Behaviour Checklist is the most widely used measure of social competence and behaviour functioning in research into the impact of childhood cancer on healthy siblings.

#### **Beck Depression Inventory-II (Beck, Steer & Brown, 1996)**

The Beck Depression Inventory-Second Edition (BDI-II) is a twenty-one item self-administered inventory employed to measure the level of an adult's depressive symptomatology (Beck et al. 1996). It is used to detect the presence and assess the severity of depression in an adult population. The BDI-II is a widely used measure,

which can be employed with both a clinical and non-clinical population. The inventory takes approximately five/ten minutes to complete (Beck et al., 1996). The twenty-one items on the inventory are; mood, pessimism, sense of failure, lack of satisfaction, guilt feelings, sense of punishment, self-dislike, self-accusation, suicidal wishes, crying, irritability, social withdrawal, indecisiveness, distortion of body image, work inhibition, sleep disturbance, fatigability, loss of appetite, weight loss, somatic preoccupation and loss of libido (Beck, Steer & Garbin, 1988). Each of the twenty-one items has four potential response statements, from which the participant selects the statement which best represents them over the prior two weeks. The four statements reflect gradations in the intensity/severity of the depressive symptoms (Wells, 1997). Each statement is assigned a corresponding score (e.g. 0–3) and all item scores are totalled to obtain an overall total score. The BDI-II manual provides clinical cut-offs; 0–13=minimal depression; 14–19=mild depression; 20–28=moderate depression; 29–63=severe depression (Beck et al. 1996). Beck et al. (1988) found that the BDI-II had: significant concurrent validity with other measures of depression (such as the Hamilton Psychiatric Rating Scale for Depression); high internal consistency in psychiatric and non-clinical populations; significant levels of test-retest reliability and was able to discriminate between different clinical groups. The BDI-II has previously been used in studies into the effects of childhood cancer on parents (as used by Brown et al. 1993; Mulhern, Fairclough, Smith & Douglas, 1992).

#### **Sibling Perception Questionnaire–Parent Version (Taylor et al. 2001)**

The Sibling Perception Questionnaire devised by Taylor et al. (2001) was a modification of Carpenter & Sahler's (1991) Sibling Perception Questionnaire used to assess healthy siblings' perceptions of their ill brother's/sister's cancer. When employed with adults, parents are asked to put themselves in the emotional position of their healthy child when responding to the statements. The parent version of the questionnaire is identical to the child/adolescent version with the exception of pronoun differences (e.g. "I think about my brother or sister's illness" becomes "*(healthy child)* thinks about his brother or sister's illness"). Taylor et al. (2001)

cited psychometric data that demonstrated the reliability and validity of the questionnaire when employed with parents.

### **2.6.3 Child/Adolescent Completed Measures**

Copies of the questionnaires/measures completed by healthy siblings are included in Appendix Five.

#### **The Child Depression Inventory (Kovacs, 1985)**

The Child Depression Inventory (CDI) is a twenty-seven item self-report measure, which is employed to assess symptoms of depression in children/adolescents aged eight to seventeen years (Kovacs, 2001). The measure quantifies depressive symptomatology including; disturbed mood, hedonistic capacity, vegetative functions, self-evaluation and interpersonal behaviours and the consequences of depression for the child (Kovacs, 1985). The CDI was found to require the lowest reading ability level of any of the measures of children's depression (Kovacs, 2001). Children/adolescents are asked to select a sentence which best represents how they have been feeling over the course of the previous two weeks. Responses are scored 0 to 2, with two representing the more severe symptomatology (Siegel, 1986). The scores are totalled and a total score is obtained. The total CDI score for a child/adolescent ranges from 0 to 54 (Siegel, 1986). The total raw score and the individual sub-scale raw scores are converted into T-Scores, which allows for comparisons across the sub-scales and across different age/gender groups. Kovacs (2001) stated that a cut-off raw score of 20 (which corresponds to a T score of between 60–65) was of clinical significance. (Appendix Seven illustrates the guidelines for interpreting the T-Scores of the CDI).

Kovacs (1985) stated that the CDI exhibited high concurrent validity against measures which assess related constructs (such as the Revised Children's Manifest Anxiety Scale ( $r=.65$ ), the Coopersmith Self-Esteem Inventory ( $r=.59$ ) and the State-Trait Anxiety Inventory for Children ( $r=.58$ ). Siegel (1986) emphasised that the CDI has good content validity with the Diagnostic Statistical Manual criteria for Major Depressive Disorder. The CDI has been found to have good internal consistency of items for both a clinical and non-clinical population (Carey, Faulstich,

Gresham, Ruggiero & Enyart, 1987; Kovacs, 2001). Finch, Saylor, Edwards & McIntosh (1987) cited the test-retest reliability of the measure as being  $r = .82$ . The CDI has been widely used in many studies investigating the impact of childhood cancer on healthy siblings (Bendavid-Strainer, 2001; Chao et al. 2003; Mulhern et al. 1992).

**Sibling Perception Questionnaire–Child/Adolescent Version  
(Carpenter & Sahler, 1991)**

The Sibling Perception Questionnaire (SPQ) is a twenty-three item questionnaire that directly assesses healthy siblings' perceptions of their ill sibling's cancer and the impact that the illness has on the family as a whole (Carpenter & Sahler, 1991). Havermans & Eiser (1994) emphasised that the SPQ is an effective way of enabling the healthy sibling to voice their opinions/concerns in a non-threatening way. Research into the psychometric properties of the SPQ established that the questionnaire was both a reliable and valid way of assessing healthy siblings' attitudes regarding cancer (Carpenter & Sahler, 1991). Factor analysis indicated that the SPQ addressed four main domains; interpersonal interactions and relationships (e.g. 'I don't want to bother my parents with my worries'), intrapersonal issues (e.g. 'I wonder why brother/sister got sick'), communication (e.g. 'I can talk to my parents about cancer') and fear of the disease (e.g. 'I worry that I can catch cancer from my brother/sister') (Carpenter & Sahler, 1991). A high score on the intrapersonal items is suggestive that the healthy sibling is concerned with how the cancer affects themselves, a high score on the interpersonal items suggests that the healthy sibling's relationship with peers and family was most significantly affected by the illness. A high score on the fear items suggested that the healthy siblings were fearful of their sibling's cancer. A high score on the communication items is suggestive that the healthy siblings felt able to discuss their sibling's illness. The questionnaire was found to be able to differentiate between well and poorly adjusted healthy siblings of children with cancer (Carpenter & Sahler, 1991).

Koocher & O'Malley (1981) stated that of one hundred and one healthy siblings of children with cancer, twenty four percent of them were unaware that their sibling's illness was cancer. Taylor et al. (2001) therefore slightly changed the wording of the

questionnaire, substituting the word 'illness' for the word 'cancer'. The initial response format of Carpenter & Sahler's (1991) questionnaire was a five-point Likert Scale (0 never to 5 always). In light of their findings that parents and children/adolescents had difficulty in identifying how often the healthy sibling experienced a particular thought/perception, Taylor et al. (2001) altered the response format to a categorical yes/no answer. They reported that this change in terminology and response format did not significantly alter the psychometric properties of the questionnaire. The SPQ has previously been employed in research into the effects of childhood cancer on healthy siblings by Eiser & Havermans (1992), Stallard et al. (1997) and Taylor et al. (2001).

## **CHAPTER THREE - RESULTS**



### **3.1 Exploratory Data Analysis**

The data was initially explored prior to statistical analysis being undertaken. The data was examined for visible gross departures from the assumptions of normality. Descriptive analysis and graphical representations of the data were generated in order to ensure that the data employed in the statistical analysis did not deviate from these assumptions. Where scores did deviate and to ensure that the assumptions required for parametric statistics could be met the specific data was transformed using a square root transformation. (Table 18, Appendix 8 illustrates the transformations performed on the data). Post-transformation of the data it was found that scores met the assumptions.

#### **3.1.1 Outliers**

Iglewicz & Hoaglin (1993) defined outliers as being unusual data values that were inconsistent with the remainder of the data set. The convention identified by Howell (1997) and Kinnear & Gray (1999) states that outliers are data with values which are two standard deviations away from the mean. Common causes/sources of outliers includes: inaccurate data recording/entry, measurement errors, incorrect distribution assumptions, unknown data structures and/or novel phenomena (Iglewicz & Hoaglin, 1993). Outliers can have a significant deleterious effect on the data itself and any statistical analysis that is subsequently performed on the data. Osborne & Overbay (2004) argued that negative consequences of outliers can includes; incorrect population parameters, increased error, distorted p-values, reduced power of statistical tests and violation of the assumptions which underlie parametric statistical tests.

Previous research has debated whether outliers should be removed from or retained within the data set (Barnett & Lewis, 1994). Osborne & Overbay (2004) argued that there is a conceptually strong argument for the removal of outliers from the data set. Undertaking statistical comparison of data with the outliers present and absent, Osborne & Overbay (2004) found that the removal of outliers lead to a reduction in error variance and produced more accurate and reliable statistical analysis. Within the present study one individual in the control group was found to be responsible for the outliers identified during exploratory data analysis. This participant's scores on

the Child Depression Inventory and Child Behaviour Checklist were found to be markedly higher than the scores of the remainder of the control group. Due to the recognition of the potential impact which such an outlier could have on the data and statistical analysis this participant's scores were removed. As only one individual was responsible for the outliers, retaining them in the original data set would have produced a control group that was not representative of the control group population as a whole.

### **3.2 Statistical Analysis**

The data was statistically analysed using the SPSS computer package. The types of statistical tests employed in this study included: Independent Sample T-Tests (to test for differences between two groups), Chi-Squares (used to identify differences between categories), Analysis of Variances (ANOVAs) (to investigate the effects of a variable under two or more conditions), Analysis of Co-Variances (ANCOVAS) (used to control for the effect of co-variables) and Multiple Regressions (a procedure which examines the extent to which it is possible for one variable to be explained/predicted by other variables).

Parametric versions of statistical tests were employed as the data was found to satisfy the assumptions that underlie parametric tests. Parametric tests were used as they are more powerful than non-parametric tests and have been found to be robust even in the face of deviations/violations of the assumptions which underlie this type of statistical analysis (Howell, 1997; Miller, 1994).

Where cited, effect sizes were calculated by subtracting the means scores for the control group from the mean scores for the oncology group and dividing this figure by the pooled standard deviation for the two groups (Howell, 1997).

When cited, tables containing analyses of the data are illustrated in Appendix Eight.

### 3.2.1 Bonferroni Test

Where multiple tests of significance (such as T-Tests or ANOVAs) are performed the true  $\alpha$  level will be significantly inflated resulting in a greater chance of obtaining a Type 1 error (Howell (1997) defined a Type 1 error as being a rejection of the null hypothesis when it is in fact true). The Bonferroni Test is a correction method which can be applied to the statistical analysis of data to reduce an inflation of a Type 1 error occurring. The Bonferroni Test is one of the simplest and most conservative statistical adjustments for multiple comparisons, additionally it is valid for analysis involving both equal and unequal sample sizes (Howell, 1997). By using a more conservative probability level (as identified by the Bonferroni method) it is possible to control for the familywise error rate which can be produced by multiple comparisons. The Bonferroni Test statistically adjusts for the familywise error by calculating a new alpha level. This new alpha level for the study is calculated by dividing the desired  $\alpha$  level by the number of dependent variables (e.g. for a desired  $\alpha$  level of 0.05, with five dependent variables the new  $\alpha$  level would be 0.01). Testing at the new  $\alpha$  level ensures that the overall chance of making a Type I error is less than the desired  $\alpha$  for the study (i.e. typically 0.05).

### 3.3 Statistical Power

The size of the study was limited due to the accessibility to participants. Previous research has found a large effect size of the psychological and behavioural impact of childhood cancer on healthy siblings (Brown et al. 1993). In line with the convention outlined by Cohen (1988, 1992), to detect a large difference between two independent samples ( $d = 0.80$ ) at the 0.05 level requires 26 participants in each group. Thus, it was proposed that a sample size of twenty-six in the oncology group and twenty-six in the control group would be sufficient to detect the anticipated effect size according to the power calculations identified by Cohen (1992).

### 3.4 Participant Details

#### 3.4.1 Number of Participants

Twenty-five individuals in the oncology group and sixty-five individuals from the control group agreed to participate. Data from three individuals in the oncology group was excluded as these participants had returned incomplete questionnaires. Seventeen individuals were not included in the control group analysis. Four individuals in the control group returned questionnaires with missing information and thirteen individuals were excluded as they did not meet the inclusion/exclusion criteria. Of these 13 excluded individuals, five health siblings were excluded as they themselves had a chronic illness (3 had asthma, 1 had Aspergers Syndrome and 1 had a learning disability) and eight were excluded as they had siblings with a chronic illness (5 had siblings with asthma, 1 had a sibling with Downs Syndrome, 1 had a sibling with a Learning Disability and 1 had a sibling with Epilepsy). (The inclusion/exclusion criteria for the research are illustrated in section 2.2.1).

Table 6 illustrates the number of participants in the oncology and control group, whose data was used in the final analysis.

**Table 6 Sample Size of Participants in the Oncology & Control Groups**

	<b>Oncology Group</b>	<b>Control Group</b>
<b>Number of Participants</b>	22 (15 families)	48 (48 families)

#### 3.4.2 Reasons for Non – Participation

The response rate for the oncology group was 24.3%, whilst the response for the control group was 10.3%. For ethical reasons (i.e. due to questionnaires being distributed anonymously) it was not possible to identify the demographic characteristics of those individuals who chose not to participate. The schools were responsible for distributing the packs to the school pupils in the control group, and whilst six hundred and thirty packs were distributed to the two schools, the individual reasons for the non-participation of individuals in the control group remains unknown. Likewise for the oncology group, as the researcher was only provided with their names and addresses, the characteristics of individuals (e.g. age,

marital and socio-economic status etc.) and the reasons for their non-participation in the research unfortunately remains unknown.

### 3.5 Participant Demographics

Parents in both the oncology and control group were asked to complete a demographic questionnaire about their healthy child and their family. (A copy of the demographic questionnaire is illustrated in Appendix Four).

#### 3.5.1 Demographics of Healthy Siblings

Table 7 illustrates the demographic characteristics of the healthy siblings in the oncology and control group:

**Table 7 Age & Gender of Healthy Siblings in the Oncology (n = 22) and Control Groups (n = 48)**

		<b>Oncology Group</b>	<b>Control Group</b>
<b>Gender</b>	<b>Female</b>	7 (31.8%)	24 (50%)
	<b>Male</b>	15 (68.2%)	24 (50%)
<b>Age</b>	<b>Mean (SD) (range)</b>	11.8 (1.9) (8-16)	11.9 (2.4) (9-16)

As shown in Table 7, the mean age for healthy siblings in both the oncology group and the control groups was around age 11. No significant difference was found in the ages of the oncology and control group ( $t=0.60$ ,  $df=68$ ,  $p=0.952$ ). A Chi-Square Test performed on the gender data indicated that there was no overall difference in the observed frequencies of males and females in the oncology and control groups ( $\chi^2=2.02$ ,  $df=1$ ,  $p=0.155$ ).

### 3.5.2 Demographics of Parents

Table Eight illustrates the demographic characteristics of the parents of the healthy siblings for the oncology and control group:

**Table 8** Demographic Characteristics of the Parents in the Oncology (n = 15) & Control Groups (n = 48)

	Oncology Group	Control Group
<b>Relationship to Healthy Sibling</b>		
Mother	11 (73%)	44 (92%)
Father	4 (27%)	4 (8%)
<b>Marital Status</b>		
Married	11 (73%)	37 (77%)
Separated	1 (7%)	4 (8%)
Divorced	0	6 (13%)
Living with Partner	2 (13%)	1 (2%)
Single	1 (7%)	0
<b>Socio-Economic Classification (SEC)</b>		
SEC 1	1 (6.7%)	6 (12.5%)
SEC 2	4 (26.7%)	17 (35.4%)
SEC 3	1 (6.7%)	8 (16.7%)
SEC 4	2 (13.3%)	6 (12.5%)
SEC 5	0	0
SEC 6	0	1 (2.1%)
SEC 7	0	1 (2.1%)
SEC 8	1 (6.7%)	1 (2.1%)
SEC 9	6 (40%)	8 (16.7%)

Mothers, for both the oncology (73%) and control groups (92%), were the parents who typically completed the questionnaires in the study. The majority of parents of participants in the oncology and control group were married (i.e. 73% of the oncology group and 77% of the control group). In both the oncology and control groups, parents tended to be characterised as being in SEC 2 (which is lower managerial and professional occupations) or SEC 9 (the title of this category is 'unclassified', but it includes housewives). It is noted that a greater percentage of parents in the oncology group were categorised in SEC 9 than were parents in the control group (i.e. 40% of the oncology group versus 16.7% of the control group).



### 3.5.3 Demographics of Ill Siblings

When completing the demographic questionnaires (Appendix Four) parents, in the oncology group, were also asked to provide demographic information regarding their ill child/adolescents. Table 9 illustrates the demographic characteristics of ill siblings in the oncology group.

**Table 9 Demographics of the Ill Siblings in the Oncology Group (n=15)**  
(Expressed as a Percentage)

	Ill Siblings
<b>Gender</b>	
Ill Female Siblings	5 (33%)
Ill Male Siblings	10 (67%)
<b>Age (in years)</b>	
Mean (SD)	9.5 (3.87)
Range	3 – 18 years
<b>Diagnosis</b>	
Acute Lymphoblastic Leukaemia (ALL)	7 (36%)
Brain Tumour	4 (27%)
Non-Hodgkins Leukaemia (NHL)	1 (7%)
Osteosarcoma	1 (7%)
Ewing's Sarcoma	1 (7%)
Neuroblastoma	1 (7%)
<b>Treatment Given</b>	
Chemotherapy	6 (40 %)
Chemotherapy & Surgery	2 (13%)
Chemotherapy & Radiotherapy	3 (20%)
Surgery & Radiotherapy	1 (7%)
Chemotherapy, Surgery & Radiotherapy	2 (13%)
Chemotherapy, Radiotherapy & Bone Marrow Transplant	1 (7%)
<b>Time Since Diagnosis – Mean (range)</b>	
	32 months (6-84 months)



Within the oncology group there was a greater proportion of male ill siblings (67%) than female ill siblings (33%). The mean age of ill siblings was 9 years. In line with previous prevalence rates for childhood cancer (Selby & Bailey, 1996), there was a higher incidence of Acute Lymphoblastic Leukaemia (ALL) (i.e. 36%) than other types of childhood cancer, with ill siblings typically being treated with chemotherapy alone (40%). The average time since the ill sibling had been diagnosed was approximately 2 ½ years.

### 3.6 Hypothesis One

*Healthy siblings of children with cancer will exhibit more psychological and behavioural difficulties than children/adolescents in a control group.*

Parents in the oncology group and control group were asked to complete the Child Behaviour Checklist (Achenbach, 1991), whilst children/adolescents in both groups were asked to complete the Child Depression Inventory (Kovacs, 1985). Table 10 illustrates the descriptive and statistical analysis of the parent completed Child Behaviour Checklist;

**Table 10 Mean (SD) & Statistical Analysis of Child Behaviour Checklist Scores for the Oncology & Control Groups<sup>10</sup>**

Sub-Scale of Child Behaviour Checklist	Oncology Group	Control Group	F-value	df	p-value
<b>Total Competence Score T-Score</b>	43.5 (10.05)	46.0 (8.7)	1.086	1,68	0.301
<b>Total Behaviour Problem T-Score</b>	50.4 (13.5)	45.0 (9.1)	3.926	1,68	0.050
<b>Internalising T-Score</b>	49.0 (8.7)	43.9 (9.8)	5.343	1,65	0.024
<b>Externalising T-Score</b>	48.1 (13.1)	45.3 (7.4)	1.332	1,68	0.253

To reduce the probability of a Type 1 error from occurring, using the Bonferroni Test, the alpha level for the above analysis was set at 0.01. Analysis of Variances

<sup>10</sup> Due to the number of dependent variables it was acknowledged that the above data could be analysed in a number of different ways, particularly Multivariate Analysis of Variance (MANOVAs) or Analysis of Variances (ANOVAs). MANOVAs are a multivariate statistical procedure which allows one to simultaneously statistically analyse the effects of multiple dependent variables (Howell, 1997). One of the perceived advantages of MANOVAs is its ability to control for the familywise Type I error, however Tabachnick & Fidell (1989) argued that this advantage over the ANOVA is eliminated when the Bonferroni correction method is applied to multiple ANOVAs. Additionally Tabachnick & Fidell (1989) also argued that the MANOVA was typically less statistically powerful than univariate analysis, particularly with small sample sizes. Tabachnick & Fidell (1989) likewise emphasised where MANOVAs produced significant results in data sets where dependent variables were correlated (as was the case in the present study) it is difficult to identify the individual contribution made by each dependent variable to the overall effect. Thus in light of the apparent difficulties associated with the MANOVA, ANOVAs (with the Bonferroni correction adjustment) were employed in order to analyse the data. (Section 3.2.1 provides further details regarding the Bonferroni Test).

performed on the Child Behaviour Checklist data indicated that at the 0.01 level there were no significant differences between the groups on the sub-scales of the checklist. Parental responses to the social competence scale of the behaviour checklist was explored further by examining whether or not the two groups significantly differed on the individual sub-scales which make up the overall social competence scale (i.e. activities, social and school). Table 11 illustrates the results of this analysis:

**Table 11 Mean (SD) & Statistical Analysis of the Sub-Scales of the Child Behaviour Checklist for the Oncology & Control Groups**

Sub-Scale	Oncology Group Mean (SD)	Control Group Mean (SD)	F-value	df	p-value
Activities	39.77 (10.8)	46.29 (8.1)	7.799	1,68	0.007
Social	47.59 (6.8)	47.9 (7.4)	0.034	1,67	0.854
School	41.41 (7.3)	43.29 (4.8)	1.674	1,68	0.200

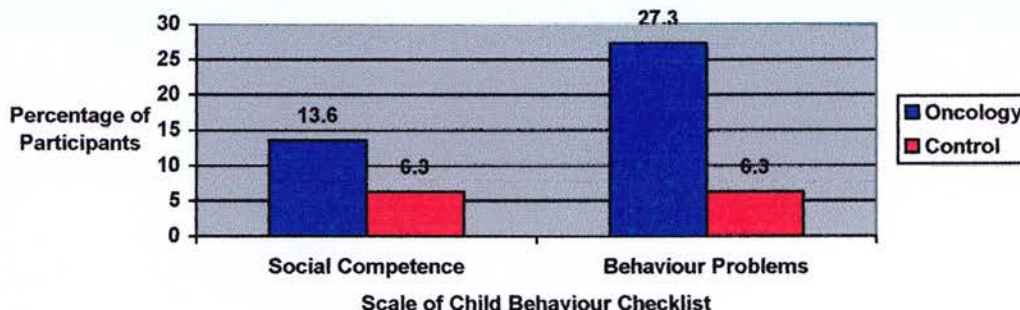
Adjusting for the familywise alpha level it was found that at the 0.01 level, whilst the two groups did not statistically significantly differ on the school ( $p=0.200$ ) and social ( $p=0.854$ ) sub-scales of the Child Behaviour Checklist, a statistically significant difference was found on the activity sub-scale ( $p=0.007$ ). Participants in the oncology group demonstrated significantly lower participation, engagement and skill in activities than were exhibited by participants in the control group.

As was discussed in section 3.2.1 the Bonferroni Test is a test that adjusts for multiple tests of significance to reduce an inflation of a Type I error from occurring. However as Howell (1997) and Osborne & Overbay (2004) emphasised whilst there is a reduced chance of a Type I error from occurring, the Bonferroni Test can actually increase the probability of a Type II error occurring.<sup>11</sup> Setting the alpha level at 0.01 results in the inflated chance that significant differences that are actually

<sup>11</sup> Howell (1997) defined a Type II error as being when the null hypothesis is accepted as true when it is actually false (i.e. saying that the independent variable(s) had no effect on the dependent variable(s) when it did).

present within the data may be missed (i.e. leading to a Type II error being committed). From the analysis detailed in table 10 it is noted that whilst there is not a significant difference between the groups on the Total Behaviour Problem Scale or the Internalising Scale at the 0.01 level there is a significant difference between the two groups at the 0.05 level. When the alpha level is set at the 0.05 level it is worth noting that children/adolescents in the oncology group were rated by their parents as exhibiting significantly more behavioural problems ( $p=0.05$ ) and experiencing significantly more internalising difficulties ( $p=0.024$ ) than their peers in the control group.

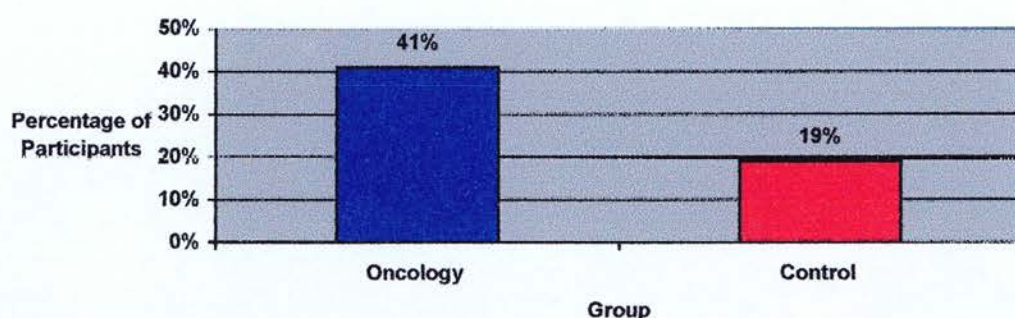
As discussed in section 2.6.2, Achenbach (1991) identified that the cut-offs for clinical significance on the Child Behaviour Checklist was a T-Score of 30 to 33 on the social competence scales and a T-score of 60 to 63 on the behaviour problem scales. As shown in Figure 2, oncology group participants were more likely, than control group participants, to score in the clinical range on both the social competence scale, (13.6% oncology versus 6.3% controls) and the behavioural problems scale (27.3% oncology versus 6.3% controls).



**Figure 2** Percentage of Participants whose T-Scores on the Child Behaviour Checklist are in the Clinically Significant Range

According to Achenbach (1991), a ten-point difference between an individual's internalising and externalising T-Score is considered clinically significant. Following Achenbach's (1991) guidelines Figure 3 illustrates the percentage of participants in the oncology and control group who exhibited a clinically significant difference between their internalising and externalising T-Scores:





**Figure 3** Percentage of Participants who Had a Clinically Significant Difference Between their Internalising and Externalising T-Scores

The results illustrated in Figure 3 demonstrate that a greater proportion of participants in the oncology group (i.e. 41%) than in the control group (i.e. 19%) had a clinically significant difference between their internalising and externalising T-Scores.

To identify if healthy siblings of children with cancer experienced greater emotional difficulties than a control group, healthy siblings in the oncology and control group were asked to complete the Child Depression Inventory (CDI). The CDI is a self-report inventory used to assess a child's/adolescent's depressive symptomatology. (Section 2.6.3 has further details regarding the CDI). Table 12 illustrates a summary of the descriptive and statistical analysis for the child/adolescent completed Child Depression Inventory:

**Table 12** Mean (SD) & Statistical Analysis of Participants' Scores on the Child Depression Inventory (for the Oncology & Control Groups)

Sub-Scale of the Child Depression Inventory	Oncology Group	Control Group	F-value	df	p-value
Total CDI T-Score	44.7 (7.3)	41.6 (4.8)	4.653	1,67	0.004
Negative Mood T-Score	47.0 (7.2)	44.6 (5.3)	1.437	1,67	0.235
Interpersonal Problems T-Score	49.5 (6.8)	45.1 (3.7)	11.625	1,65	0.001
Ineffectiveness T-Score	45.2 (6.2)	41.7 (7.2)	3.946	1,67	0.005
Anhedonia T-Score	44.5 (7.4)	41.3 (5.1)	4.502	1,67	0.003
Negative Self-Esteem T-Score	46.1 (7.2)	45.4 (5.7)	0.184	1,67	0.669

To reduce the probability of a Type I error occurring, using the Bonferroni Test, the alpha level for the Child Depression Inventory analysis was set at 0.01. In order to investigate if there was a significant difference in the self-reported depressive symptomatology of participants in the oncology and control group, ANOVAs were performed on the CDI total and sub-scale scores. This analysis indicated that healthy siblings in the oncology group had significantly higher Total CDI T-Scores than siblings in the control group (Table 12). A Post-Hoc Power Analysis identified a medium effect size for the level of depressive symptomatology in healthy siblings of children with cancer.

Further exploration of the different sub-scales of the CDI indicated that the oncology group scored statistically significantly higher than the control group on the interpersonal problems, ineffectiveness and anhedonia scales at the 0.01 level. No significant difference was found between the two groups in the negative mood and negative self-esteem scales of the CDI ( $p > 0.01$ ). As was discussed in section 2.6.3, a raw score of 20 with a corresponding Total CDI T-Score of 60–65 has been recommended as a cut-off point for clinical significance (Kovacs, 2001). No participants in the control group had Total CDI T-scores which were clinically significant, whilst one individual in the oncology group had a clinically significant raw score of 20 with a corresponding Total CDI T-Score of 63.

### **3.6.1 Effect of Background Factors on Healthy Siblings' Psychological & Behavioural Functioning & Adjustment**

In order to identify if there was an effect of background factors (i.e. age and gender of healthy sibling and marital and socio-economic status of parents) on the Child Depression Inventory (CDI) and Child Behaviour Checklist data, Analysis of Co-Variates (ANCOVA) were performed on the oncology and control group data. Appendix Eight (Tables 21 to 25) illustrates the results of the ANCOVAs performed on the data to investigate the effects of background demographic factors.

It was found that there was no significant relationship between parents' marital and socio-economic status and the healthy siblings' scores on the sub-scales of the Child Behaviour Checklist and the Total CDI T-Score ( $p>0.05$ ).

However a significant effect of the gender of the healthy siblings was found on their Behaviour Problem T-Scores ( $F(1,67)=4.974$ ,  $p=0.029$ ) and their Internalising T-Scores ( $F(1,64)=4.269$ ,  $p=0.043$ ) on the Child Behaviour Checklist. Table 13 illustrates the mean female/male scores for the oncology and control groups' Behaviour Problem T-Scores and Internalising T-Scores:

**Table 13** Mean (SD) Scores on the Behaviour Problem and Internalising Scales for Females & Males in the Oncology and Control Group

	Oncology Group		Control Group	
	Females	Males	Females	Males
<b>Behaviour Problem T-Score</b>	46.09 (9.21)	51.27 (8.32)	41.01 (11.43)	46.41 (6.62)
<b>Internalising T-Score</b>	46.71 (16.95)	52.13 (11.99)	41.57 (8.36)	47.83 (8.67)

The results indicated in Table 13 illustrated that parents in both the oncology and control group rated male healthy siblings as exhibiting more behavioural problems and internalising difficulties than females in either group. Compared to all groups male healthy siblings in the oncology group were rated as having the most behavioural problems.

As is illustrated in Appendix Eight ANCOVAs performed on the data indicated that there was a significant effect of the age of the healthy siblings on their scores on the Externalising Scale of the Child Behaviour Checklist ( $F(1,67)=3.827$ ,  $p=0.042$ ). It was observed that healthy siblings aged 13 years and over in the oncology group exhibited higher externalising scores (mean=51.56, SD=13.90) than healthy siblings of the same age in the control group (mean=48.87, SD=9.29). Older healthy siblings in the control group also scored higher than healthy siblings 12 years and under in both the oncology group (mean=45.77, SD=12.45) and control group (mean=43.59, SD=5.85) on the externalising scale of the Child Behaviour Checklist.



### 3.6.2 Summary of Hypothesis One

Hypothesis One stated that *Healthy siblings of children with cancer will exhibit more psychological and behavioural difficulties than children/adolescents in a control group*. Analysis of Variances performed on the data indicated that at the 0.01 alpha level there were no significant differences between the oncology and control groups with regards to their scores on the four sub-scales of the Child Behaviour Checklist (i.e. the Social Competence, Behaviour Problems, Internalising Difficulties and Externalising Difficulties). As was discussed in section 3.6 whilst the Bonferroni Test reduces the probability of a Type I error occurring it can lead to an increase in the probability of a Type II error being committed. From an exploration of the data it is noted that at the 0.05 level there were significant differences between the groups on their scores for the Behaviour Problem Scale ( $p=0.050$ ) and the Internalising Scale ( $p=0.024$ ). There is apparent research and clinical relevance in recognising that at the 0.05 level children/adolescents with siblings with cancer were rated (by their parents) as exhibiting and experiencing significantly more behavioural problems and internalising difficulties than children/adolescents in a control group. With increased power in future studies it would be possible to investigate these findings further.

Further analysis of the individual sub-scales of the Social Competence Scale of the Child Behaviour Checklist identified that healthy siblings in the oncology group participated in significantly less and demonstrated significantly less skill in activities (such as hobbies and sports) than healthy siblings in the control group ( $p=0.007$ ). Greater proportions of healthy siblings in the oncology group were found to have Behaviour Problem T-Scores and Social Competence T-Scores in the clinical range than was the case for healthy siblings in the control group.

On a self-report examining depressive symptomatology (the CDI) healthy siblings in the oncology group reported themselves as being significantly more depressed than siblings in a control group ( $p=0.004$ ). Children/adolescents within the oncology group reported particular depressive symptomatology with regards to interpersonal problems, feelings of ineffectiveness and anhedonia.

Statistical analysis performed on the data indicated that there was a significant effect of the healthy siblings' gender on the Behaviour Problem and Internalising Scales of the Child Behaviour Checklist. With male healthy siblings in the oncology group exhibiting greater behavioural problems and internalising difficulties than females in the oncology group and than all participants in the control group. Age of healthy siblings was found to have a significant effect on participants' scores on the Externalising Scale of the Child Behaviour Checklist. It was noted that healthy siblings thirteen years and over in the oncology group exhibited the most externalising behaviours.

Healthy siblings of children with cancer were not found to have more behavioural difficulties than a control group at the 0.01 level. However they were found to have more behavioural problems and internalising difficulties than the control group at the 0.05 level. Healthy siblings in the oncology group rated themselves as being significantly more depressed than healthy siblings in the control group at the 0.01 level. These results suggest support for the hypothesis that healthy siblings of children with cancer will exhibit more psychological difficulties than children/adolescents in a control group, however the findings regarding whether or not healthy siblings of children with cancer will experience more behaviour problems is inconclusive.

### 3.7 Hypothesis Two

*Parents and healthy siblings will disagree regarding the impact of childhood cancer on healthy siblings.*

To explore whether parents and healthy siblings will disagree regarding the impact of cancer on the healthy siblings, both parents and healthy siblings, in the oncology group, were asked to complete the Sibling Perception Questionnaire (SPQ) (Carpenter & Sahler, 1991). The child/adolescent version of this questionnaire was designed to assess the negative and positive attitudes of healthy siblings of children with cancer. Taylor et al. (2001) developed a parent version of the measure, whereby parents were asked to put themselves in the emotional position of their healthy child. The mean scores for each of the four sub-scales and the overall score for the SPQ were calculated for the parents and healthy siblings within the oncology group. Table 14 illustrates these scores:

**Table 14 Mean (SD) & Statistical Analysis of Healthy Siblings' and Parents' Scores on the Sibling Perception Questionnaire (SPQ) (Oncology Group) (n=22)**

Domain	Healthy Siblings	Parents	F-value	df	p-value
<b>Total SPQ Score</b>	10.0 (2.8)	10.8 (1.8)	1.059	1,42	0.309
<b>Interpersonal Score</b>	4.1 (1.7)	4.5 (1.1)	0.502	1,42	0.482
<b>Intrapersonal Score</b>	2.6 (0.9)	3.5 (0.8)	<b>5.843</b>	<b>1,42</b>	<b>0.002</b>
<b>Communication Score</b>	1.7 (0.8)	1.5 (0.8)	1.007	1,42	0.321
<b>Fear of Disease Score</b>	1.4 (0.7)	1.2 (0.6)	0.857	1,42	0.360

In line with Taylor et al.'s (2001) analysis of the SPQ, ANOVAs were performed on the data in order to identify if there were statistically significant differences in the healthy siblings' and parents' total and domain SPQ scores. This analysis indicated that for the overall Total SPQ scores there were no statistically significant differences between the healthy siblings and parents in the oncology group ( $p=0.309$ ). In an analysis of the differences in domain scores, there was a statistically

significant difference between healthy siblings' and parents' scores on the intrapersonal domain ( $p=0.002$ ), but not on the interpersonal, communication and fear of disease domains ( $p>0.01$ ) (Table 14).

There was marked variability in the healthy siblings' and parents' agreement on specific items of the SPQ. (Table 26, Appendix Eight illustrates the Healthy Sibling-Parent Percentage of Agreement/Disagreement on the Negative Attitudes Experienced by Healthy Siblings). High variability in the healthy sibling-parent percentage agreements was found on items that addressed attitudes regarding the emotional impact of the illness on healthy siblings. Whilst there was 100% agreement that the healthy sibling wished there was something they could do about their sibling's illness, only 54.5% of healthy siblings-parents pairs agreed on whether or not the healthy sibling is able to forget about the illness. With regards to this item whilst only 1 of healthy siblings reported that they were unable to forget about their sibling's cancer, 9 parents reported that they believed their healthy child to be unable to forget about the cancer. High healthy sibling-parent percentage agreement was found on those items associated with the healthy siblings' fears about the illness. Indeed, 86% of pairs of healthy siblings and parents agreed on whether or not the healthy sibling worried about catching their sibling's illness and about whether or not the healthy siblings thought their friends worried that they could 'catch' the illness. Lower healthy sibling-parent percentage agreement was found on items that were related to the healthy siblings' attitudes about their interactions with others. For example, there was only 54.5% healthy sibling/parent agreement about whether or not the healthy siblings wanted to bother their parents with their worries.

Analysis of the SPQ indicated that healthy siblings and parents in the oncology group did not significantly differ regarding their views about the negative perceptions held by the healthy sibling regarding the cancer. However in order to identify if parents and healthy siblings in the oncology group disagreed regarding the emotional functioning of the healthy siblings, a Pearson's Correlation was performed on the healthy sibling completed CDI and the parent completed Internalising Scale of the Child Behaviour Checklist. (As discussed in section 2.6.2 the Internalising Scale of

the Child Behaviour Checklist asks parents questions regarding the emotional, withdrawal and somatic problems experienced by healthy siblings). The results of this analysis of the oncology group data indicated that there was a significant positive correlation between the CDI T-Score and the Internalising T-Score ( $r=0.448$ ,  $n=21$ ,  $p=0.021$ ). This positive correlation indicated that there was a relationship between the CDI and Internalising Scale data, with parents and healthy siblings typically agreeing regarding the emotional consequences of childhood cancer on healthy siblings.

### **3.7.1 Summary of Hypothesis Two**

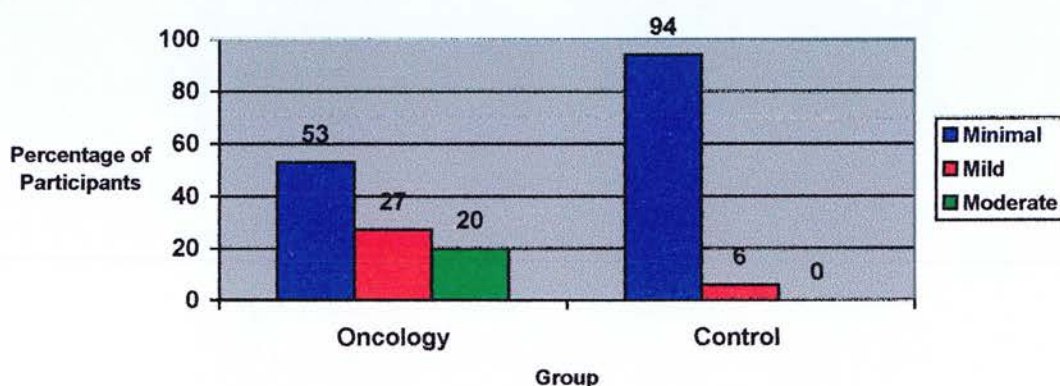
The SPQ employed in the present study has been used in previous studies to identify the level of agreement/disagreement between healthy siblings and parents with regards to the negative attitudes and perceptions experienced by healthy siblings of children with cancer (Taylor et al. 2001). Statistical analysis of the SPQ Total Scores and the domain scores indicated that (with the exception of the intrapersonal domain) there was no significant differences/disagreement between healthy siblings–parents regarding the negative perceptions held by healthy siblings regarding their sibling’s cancer. The positive correlation found between the parent completed Internalising scale of the Child Behaviour Checklist and the healthy sibling completed Child Depression Inventory indicated a relationship between the two measures. As parents and healthy siblings, in the oncology group, were not found to disagree with regards to the impact of the cancer on healthy siblings, hypothesis two that parents and healthy siblings will disagree regarding the impact of childhood cancer on healthy siblings was rejected.



### 3.8 Hypothesis Three

*Parents of healthy siblings in the oncology group will be significantly more depressed than parents of healthy siblings in the control group.*

In order to identify if parents in the oncology group were more depressed than parents in the control group, an Independent Sample T-Test was performed on both groups parent completed Beck Depression Inventory-II scores. The BDI-II scores for parents in the oncology group was significantly higher (mean=14.06, SD=8.407) than the BDI-II scores of parents in the control group (mean=5.56, SD=5.422) ( $t=4.767$ ,  $df=63$ ,  $p=0.001$ ). As was discussed in section 2.6.2, Beck et al. (1988) provided cut-off scores for the four clinical ranges of the Beck Depression Inventory-II (i.e. minimal, mild, moderate and severe depression). Figure 4 illustrates the percentage of parents in the oncology and control group who scored within these ranges:



**Figure 4 Percentage of Parents whose BDI-II Scores Fell Within the Clinical Ranges**

As is illustrated in Figure 4 a larger proportion of the oncology group scored either in the mild or moderate range than compared to those parents in the control group who scored in these ranges. A Post-Hoc Power Analysis found a large effect size for the

level of depressive symptomatology in parents of healthy siblings in the oncology group.

### **3.8.1 Summary of Hypothesis Three**

As was predicted by hypothesis three parents in the oncology group were statistically significantly more depressed than parents of healthy siblings in the control group. The results of this analysis provided evidence in support of hypothesis three.



### 3.9 Hypothesis Four

*The psychological and behavioural functioning of healthy siblings of children with cancer will be significant variables in predicting the psychological functioning of their parents*<sup>12</sup>.

As Brace et al. (2003) identified multiple regression is a statistical procedure that can indicate the extent to which one variable can be explained or predicted by one or more other variable(s). A hierarchical multiple regression (also known as a step-wise multiple regression) is a regression procedure that creates a model identifying the smallest number of variables required for predicting another variable.<sup>13</sup> In order to establish whether or not the psychological and functioning of healthy siblings of children with cancer will be significant variables in predicting the psychological functioning of their parents a hierarchical multiple regression was performed on the data.

Using the stepwise method, a significant model emerged ( $F(2,61)=13.221, p=0.001$ ). With an adjusted  $R^2=0.280$ , the variables which were found to significantly predict the psychological functioning of parents in the oncology group are illustrated in Table 15;

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<sup>12</sup> For the purposes of this correlation the raw scores of the Child Behaviour Checklist and the Child Depression Inventory were employed rather than the converted T-Scores. As Achenbach & Brown (1991) acknowledged T-Scores can be useful when comparing the scores of other individual of the same gender and within the same age range. However they recognised that the raw scores reflected greater differences amongst participants than is typically reflected by T-Scores (for example, a wide range of raw scores can be represented by the same T-Score). In light of the fact that the correlational analyses undertaken in the present hypothesis involved the BDI-II (which does not convert raw scores to T-Scores) it was considered appropriate to follow Achenbach & Brown's recommendations and thus raw scores were used.

<sup>13</sup> As Tabachnik & Fidell (1989) stated "Regression will be best when each independent variable is strongly correlated with the dependent variable but unaffected with other independent variables. A general goal of regression, thus is to identify the fewest independent variables necessary to predict a dependent variable where each independent variable predicts a substantial and independent segment of the variability in the dependent variable." (pg. 116).

**Table 15**                      **Results of the Multiple Regression Performed on the Data**

<b>Predictor Variable</b>	<b>Beta</b>	<b>p-value</b>
<b>Behaviour Problem Raw Score</b>	0.443	0.001
<b>Social Competence Raw Score</b>	0.203	0.040

The results of the multiple regression performed on the data indicated that whilst healthy sibling's Behaviour Problem and Social Competence Raw Scores were significant predictors of parents' Beck Depression Scores, healthy siblings' CDI scores and Internalising and Externalising Scores were not significant variables in predicting depressive symptomatology in their parents.

### **3.9.1                      Summary of Hypothesis Four**

The results of the multiple regression performed on the data provided evidence for a partial acceptance of hypothesis four. Whilst healthy siblings' level of depressive symptomatology and the extent of their internalising/externalising difficulties were not significant variables which were predictive of their parents experiencing psychological difficulties, the presence of behaviour problems and the level of social competence functioning were variables that were predictive of parental psychological difficulties.

## **CHAPTER FOUR - DISCUSSION**

## 4.1 SUMMARY OF RESEARCH

Whilst the psychological effects of childhood cancer on healthy siblings have been the focus of a limited number of previous research studies, very few of these earlier studies employed both standardised measures and a control group (Houtzager et al. 1999).

The present study investigated the psychological effects of childhood cancer on healthy siblings compared to a control group. In order to enable the findings of the present research to be compared with previous studies, commonly used measures of depression and behavioural/social functioning were employed.

The present research indicated that there was no significant difference in the level of behaviour problems exhibited by the oncology and control group at the 0.01 level. However in comparison to a control group healthy siblings of children with cancer were found to exhibit statistically significantly more psychological difficulties. Likewise parents in the oncology group were found to have statistically significantly more depressive symptomatology than was reported by parents in a control group. Marital and socio-economic status of parents were not found to have a significant effect on healthy siblings' functioning and adjustment. Healthy siblings who were male and healthy siblings who were over thirteen years of age in the oncology group were found to be at particular risk of exhibiting greater behaviour problems relative to the control group and females and siblings under twelve in the oncology group. Parents and healthy siblings in the oncology group were not found to significantly differ with regards to their views on the impact of cancer on healthy siblings. Within the healthy siblings of children with cancer population scores on the Behaviour Problem and Social Competence Scale were found to be significant variables predictive of parental depression. However healthy siblings' scores on the Child Depression Inventory, and the Internalising and Externalising sub-scales of the Child Behaviour Checklist did not contribute significantly to the model when the behaviour problem and social competence variables had been added.

### 4.1.1 Hypothesis One

*Healthy siblings of children with cancer will exhibit more psychological and behavioural difficulties than children/adolescents in a control group*

Healthy siblings' scores on the Social Competence, Behaviour Problems, Internalising and Externalising scales of the Child Behaviour Checklist were not found to be significantly different between the two groups at the 0.01 level. These findings contrast with earlier research by Cohen et al. (1994), Sahler et al. (1994) and Sloper & While (1996) which found that healthy siblings of children with cancer exhibited elevated levels of behaviour problems relative to a control group. The results of the present study does however support the findings of research by Dolgin & Phipps (2000) and Sawyer, Antonious, Toogood, Rice & Baghurst (1997) which likewise found that healthy siblings of children with cancer were not at an increased risk of developing behavioural difficulties.

The Bonferroni Test is a conservative test which reduces the likelihood of Type I errors, but at the expense of increasing the likelihood of Type II errors (Osborne & Overbay, 2004). Thus the use of this test reduces the likelihood of identifying false positives, but increases the risk that genuine differences between groups will not be detected. Consideration of actual p values indicates differences between the two groups on the Behaviour Problem scale ( $p=0.05$ ) and the Internalising sub-scale ( $p=0.024$ ). Whilst not statistically significant at the 0.01 level, larger studies would be required to clarify this issue, healthy siblings of children with cancer may be at elevated risk of developing behavioural difficulties.

The data of the present study indicated no significant differences between the two groups with regards to the level of participants' social competence functioning. These findings replicate Horowitz & Kazak's (1990) findings however they contrast with research by Cohen et al. (1994) and Wang & Martinson (1996) which found that healthy siblings of children with cancer typically displayed significantly reduced social competence functioning, relative to a normative sample (of individuals without cancer). In the present study, healthy siblings of children with cancer were rated, by

their parents, as having significantly less participation, engagement and skill in activities than healthy siblings in a control group (as found by Lavigne & Ryan, 1979; Williams et al. 1993). The reduced engagement and participation in activities exhibited by healthy siblings of children with cancer may be due to a number of different reasons. For example, with their siblings' frequent periods of hospitalisation, healthy siblings may be increasingly cared for outwith their own home (thus limiting their opportunity to engage in activities) (Perrin, Stern & Drotar, 1991). Healthy siblings of children with cancer may be expected/compelled to adopt care-giving roles and responsibilities within the family unit, resulting in a reduction in the amount of free time they have available to engage in activities such as sports and hobbies (Boyce & Barnett, 1993; Gold, 1993). In contrast to Labay's (2002) and Taylor's (1980) findings, having a sibling with cancer did not appear to cause the present study's healthy siblings to experience significantly more difficulties at school than were displayed by a control group.

On the CDI measure of depressive symptomatology in children/adolescents, healthy siblings of children with cancer were found to be significantly more depressed than healthy siblings in a control group. Whilst Cairns et al. (1979) found elevated rates of depressive symptomatology in healthy siblings of children with cancer Van Dongen-Melman et al. (1995) did not find that healthy siblings of children with cancer scored significantly higher on the CDI. Analyses of the sub-scales of the CDI indicated that there were no differences between the two groups with regards to the levels of their negative mood and negative self-esteem. However healthy siblings of children with cancer were found to score significantly higher on items measuring interpersonal problems, feelings of anhedonia and ineffectiveness.

The high level of depressive symptomatology found in healthy siblings of children with cancer is clearly worrisome, particularly as the internalised nature of depression may result in a situation where the emotional difficulties of healthy siblings of children with cancer go unnoticed by parents and health professionals. At a time when their family is experiencing significant levels of trauma and difficulties, the healthy siblings of children with cancer may themselves be unwilling to identify the

difficulties they are experiencing. They may perceive their difficulties to be 'minor' in comparison to their sibling's illness and they may view their problems to be an unnecessary burden for the rest of the family (Powazek, Payne, Goff, Paulson & Stagner, 1980). The fact that healthy siblings of children with cancer report themselves as having high levels of depressive symptomatology should be viewed as an important target for future clinical interventions with this population.

### **Effects of Background Factors on Healthy Siblings' Psychological & Behavioural Functioning & Adjustment**

Statistical analysis of the data indicated that male healthy siblings of children with cancer exhibited significantly more behaviour problems and internalising difficulties than females and than males and females in the control group. An effect of age of healthy siblings was found, with healthy siblings aged thirteen years and over displaying significantly more externalising behaviours than younger siblings in the oncology group and all siblings in the control group. These results suggest that healthy siblings who are male and healthy siblings who are over thirteen years may be at particular risk of developing difficulties. However, it is important to note that the higher number of males (15) than females (7) in the oncology group leads to a need for caution in the extent to which the results are generalisable across the population of healthy siblings of children with cancer.

The present study's results challenge the findings of previous research which argued that younger healthy siblings were at a significantly elevated risk of developing behavioural problems as a result of their sibling's cancer (Cohen, 1985; Sahler et al., 1994; Von Essen & Enskar, 2003). The results of the present research does however support the work of Bendor (1990) and Skidmore (1996) who reported that healthy siblings, who were adolescents, had a significantly poorer outcome than healthy siblings who are in the middle childhood period of development. Adolescence poses a number of developmental challenges for individuals (section 1.7). Not only will adolescents possess a better conceptualisation and understanding of cancer (and thus the potential terminal nature of the condition) but having a sibling with cancer may



also leave them unable to become independent from the family. Whilst the adolescent healthy sibling has to confront their sibling's cancer, they will also be faced with the developmental tasks inherent within adolescence (including physical, sexual and interpersonal maturation etc.) The additive effect of these combined pressures may prove difficult for the adolescent to cope with in an effective and adaptive way, resulting in the adolescent engaging in problem behaviours in an attempt to deal with their difficulties.

The finding that male healthy siblings displayed higher levels of behaviour problems than females is comparable with the findings of Sahler et al. (1994) and Sargent et al. (1995), whereas Barbarin et al. (1995) found no such effect. Based on previous research it had been anticipated that males would display significantly higher scores than females and older participants significantly higher than younger participants, on the CDI (Finch, Saylor & Edwards; 1985, Reinherz, Stewart-Berghauer, Paskiz, Frost, Moeykes & Holmes, 1989). However, in the current study, age and gender did not have significant effects on the level of depressive symptomatology exhibited by healthy siblings of children with cancer. Faust, Baum & Forehand (1985) and Gates, Lineberger, Crockett & Hubbard (1988) obtained similar results in their research with the general population.

Previous research has found that high socio-economic status is a significant protective factor against the healthy sibling developing difficulties as a result of their sibling's cancer (Koocher & O'Malley, 1981). It was therefore anticipated that healthy siblings from lower socio-economic families would display significantly greater adjustment difficulties than healthy siblings from higher socio-economic status (Sloper & While, 1996; Thompson et al. 1994). However, the results obtained in the present study found no significant effect of socio-economic status on the adjustment and functioning of healthy siblings. Parents in the oncology group were however more likely to be in SEC 9 (i.e. 'unclassified' category, including housewives), whereas the control group had a high prevalence of parents classified as SEC 2 (i.e. 'lower managerial and professional occupations').

These differences may reflect socio-economic changes that occurred as a consequence of the diagnosis of cancer rather than reflecting pre-diagnosis socio-economic status, as parents within the oncology group may have experienced a change in their employment (and thus their socio-economic classification) status as result of the cancer diagnosis. For with the cancer diagnosis parents may have given up their jobs to care for their ill child (Sloper, 1996). The socio-economic status of the control group was somewhat higher than the average for the local area (NHS Tayside, 2003a). It may be the case that the high socio-economic statuses of participants in the control group, is a reflection more of the types of individuals who typically agree to participate in research than of the general population within that area.

Marital status of parents was not found to have a significant effect on the psychological and behavioural functioning of healthy siblings. This contrasts with research by Thompson et al. (1994) who found that healthy siblings from two-parent families were significantly less likely to experience difficulties than children/adolescents from one-parent families. Whilst marital status was not found to have a significant effect within the present research, the majority of parents in both the oncology group (73%) and the control group (92%) were in fact married. In the present study there were insufficient numbers of one-parent families for an exploration of the differential effects that two-parent versus one-parent families can have on healthy siblings of children with cancer to be undertaken. Future research, with larger and more heterogeneous sample sizes, could explore further the way in which the nature and structure of the family unit can impact on the functioning and adjustment of healthy siblings of children with cancer.

### 4.1.2 Hypothesis Two

*Parents and healthy siblings will disagree regarding the impact of childhood cancer on healthy siblings*

The results of the present study found that healthy siblings and their parents typically agreed regarding whether or not the healthy sibling possessed negative perceptions/attitudes on the interpersonal, communication and fear of disease domains of the Sibling Perception Questionnaire. These findings contrast with Taylor et al.'s (2001) study that found that parents rated their healthy children as possessing significantly more negative perceptions than was identified by the healthy siblings themselves.

The present research did however find significant differences between healthy siblings and parents regarding the intrapersonal impact that the cancer had on the healthy siblings. These differences within the intrapersonal domain included items concerned with the impact of cancer on the healthy sibling's thoughts, emotions and their coping strategies (e.g. the healthy sibling's anger towards the cancer and the healthy sibling's ability to forget about the diagnosis). Denial and avoidance of the problems and the healthy siblings' desire to protect their parents from further worry may be factors in producing the disagreements between healthy siblings and parents regarding the intrapersonal impact of cancer on the healthy sibling.

The SPQ has been used in a number of previous studies of the impact which childhood cancer can have on healthy siblings. As Houtzager et al. (1999) stated, no other measure/assessment has been specifically designed to assess the negative perceptions of healthy siblings of children with cancer. The lack of any other suitable measure and the standardisation data cited by Carpenter & Sahler (1991) suggested that the questionnaire would be a useful way of obtaining more detailed information regarding the negative perceptions held by healthy siblings of children with cancer. However, a number of difficulties associated with the questionnaire challenge the extent to which it can be considered to be a sufficiently sensitive, reliable and valid measure. The different ways in which the questionnaire has been

scored leads to difficulties in the extent to which comparisons of the questionnaire can be made across different research studies (Carpenter & Sahler, 1991; Taylor et al. 2001). For example whilst Carpenter & Sahler (1991) scored the data on a five-point Likert Scale, Taylor et al. (2001) employed a yes/no answer format. Carpenter & Sahler (1991) provided information regarding the reliability and internal consistency of the questionnaire. However, Sloper & While's (1996) research cited alpha coefficients for the internal consistency of the questionnaire as being as low as 0.48 and 0.44 for the communication and fear domains. This low level of internal consistency of the SPQ clearly leads to a need for caution in the extent to which the measure is employed and the extent to which generalisations can be made from the findings of the questionnaire.

A positive correlation was found between parent and healthy sibling completed measures of the healthy sibling's emotional difficulties (i.e. as measured by the Internalising Scale of the Child Behaviour Checklist and the Child Depression Inventory). High scores on the Internalising Scale were correlated with high scores on the CDI. These results suggest that there was typically agreement between parents and healthy siblings regarding the presence of internalising difficulties in healthy siblings of children with cancer and thus hypothesis two was not supported. In contrast to Cairns et al.'s (1979) and Walker's (1988) research, the present study found that parents were typically able to recognise the presence of difficulties experienced by healthy siblings.

It is recognised that it would be preferable for parents and children to complete questionnaires that are more directly comparable with one another. Therefore comparisons between the Child Depression Inventory and the modified parent version of the CDI may allow for a more reliable comparison to be made with regards to the level of agreement/disagreement between healthy siblings and parents (Wierzbicki, 1987). Likewise, a comparison of the parent completed Child Behaviour Checklist and the Youth Self-Report Version of the measure (Achenbach, 1991) would enable more direct comparisons of agreement/disagreement regarding

the impact of cancer on the healthy siblings' behavioural and social competence functioning to be made.

### **4.1.3 Hypothesis Three**

*Parents of healthy siblings in the oncology group will be significantly more depressed than parents of healthy siblings in the control group*

Diagnosis of childhood cancer poses a considerable challenge for the entire family unit, on the ill child, their parents and their brothers/sisters. It was hypothesised that parents in the oncology group would be significantly more depressed than parents in the control group. The results supported hypothesis three, as parents of children/adolescents in the oncology group were found to be significantly more depressed than their counterparts in the control group and were more likely to have scores within the clinical ranges of the Beck Depression Inventory-II. A higher prevalence of depression in parents of children with cancer has been found in previous studies (Kupst & Schulman, 1988; Maguire, 1983).

Significant levels of depression in parents of children with cancer have implications for clinical practice. Particularly as parental depression can heighten the risk of emotional and behavioural problems in children/adolescents (Gelfand & Teti, 1990) and can significantly impact on their parenting ability (Goodman & Brumley, 1990) and the attachment/relationship with their healthy children (Murray, 2000a). At a time when they need parental support, having a parent with depression may exacerbate the healthy sibling's difficulties and may limit the extent to which they are able to deal with the difficulties they are experiencing as a result of their sibling's cancer. Consequently, assessment/monitoring of the whole family is vital in ensuring that they are able to effectively and adaptively adjust to the diagnosis. Such families should be offered appropriate support, which may include input from a clinical psychologist when deemed necessary.

It is important to note that BDI-II scores for the control group in the present study were markedly lower than those of Beck et al.'s (1996) comparison normal group.

Thus the possibility arises that the type of participants who agreed to participate in the control group are not entirely representative of the wider population (as demonstrated by their relatively low depressive symptomatology). Hence, caution is required in the extent to which the control group's BDI scores are interpreted and generalised.

#### **4.1.4 Hypothesis Four**

*The psychological and behavioural functioning of healthy siblings of children with cancer will be significant variables in predicting the psychological functioning of their parents.*

A Hierarchical Multiple Regression was performed on the Beck Depression Inventory, the Child Depression Inventory and the Child Behaviour Checklist. Based on previous research (Lefkowitz & Tesiny, 1985), it had been anticipated that there would be a relationship between the depressive symptomatology of parents and the behavioural and psychological difficulties of healthy siblings of children with cancer. The results of the multiple regression indicated that healthy siblings' scores on the Behaviour Problem and Social Competence scales of the Child Behaviour Checklist were significant predictors of parental depression. Healthy siblings' scores on the Child Depression Inventory and the Internalising and Externalising scales of the Child Behaviour Checklist were not found to be significant variables that were predictive of the psychological functioning of parents. The results of the present study support the findings of Mulhern et al. (1992) which found that increased behavioural problems in healthy siblings of children with cancer were predictive of depressive symptomatology in parents.

A parents' perception of the functioning and adjustment of their child/adolescent is influenced by a number of factors, particularly their own adaptation and psychological functioning (Verte et al., 2003). According to Bugental & Cortez (1988), parental depression can limit the parent's capacity to adequately supervise and support their child/adolescent. From a cognitive therapy perspective, the negative thoughts of oneself, the world and the future is a central characteristic of



depression (Beck, Rush, Shaw & Emery, 1979). The significant incidence of depression in parents in the oncology group leads to a need for caution in the extent to which the Child Behaviour Checklist is viewed as being an entirely objective portrait of the behaviour problems exhibited by healthy siblings of children with cancer (Cohen et al. 1994). For as Hops, Biglan, Sherna, Arthur, Friedman & Osteer (1987) identified depressed parents' rumination, preoccupation and self-absorption may make them inattentive to the behavioural functioning of the healthy siblings. Whilst Parke & Tinsley (1987) argued that depressed parents' negative perception of themselves and others may make them hypercritical and selectively attentive to the healthy sibling's misbehaviour. It would therefore be beneficial for future research in this area to obtain an independent rating of the healthy sibling's behaviour from other sources (e.g. such as with the Teachers' Version of the Child Behaviour Checklist). By obtaining information regarding healthy siblings' behaviour from other sources it would be possible to corroborate the reports provided by parents regarding the child's/adolescent's behaviour. Accruing additional information from other sources would enable future research to be undertaken in identifying the extent to which depressed parents possess realistic or distorted views of their child's/adolescent's behaviour functioning.

## **4.2 METHODOLOGICAL ISSUES**

### **LIMITATIONS OF THE RESEARCH**

A number of limitations in the methodological design of this research were identified:

#### **4.2.1 Effect Size**

Based on research by Brown et al. (1993) it had been anticipated that a large effect size would be obtained in this research. However, post-hoc power calculations performed on a number of measures in the study generally identified a small effect size of the impact of childhood cancer on healthy siblings ( $d=0.20$ ). This effect size is comparable with Sharpe & Rossiter's (2002) research that identified that the magnitude of the effect size for healthy siblings of children with chronic illness was small. According to Cohen (1992) a sample size of three hundred and ninety-three participants would be required to detect a small effect size. The present study's response rate for the oncology group (i.e. 24.3%) would require a pool of approximately one thousand six hundred and twenty participants who met the exclusion/inclusion criteria. To obtain such numbers would require and involve a multi-site and multi-disciplinary research study to be undertaken. Obtaining a small effect size requires caution in conclusions/clinical implications which are drawn from the research findings (Bendor, 1990). The practicality and viability of the requirements of such a study would clearly be questionable, particularly with regards to its time, financial and labour implications and clinical efficacy (Howell, 1997).

#### **4.2.2 Selection Bias**

A further potential limitation of the present study is the potential selection bias of participants who consented to participate in the research. In order to meet the British Psychological Society's (BPS) (2000) Ethical Principles for Conducting Research with Human Participants participation in the research was entirely voluntary. As Stallard et al. (1997) identified, reliance on individuals volunteering to participate in research studies automatically leads to a selection bias. Hollidge (2001) highlights that there may be specific traits/characteristics of individuals who participate in research versus those who do not consent to take part. It has been argued that individuals who participate in research are often typically those families who are

better adjusted and are experiencing fewer difficulties than those who do not participate (Alderfer et al, 2003). In contrast, Breyer et al. (1993) argued that it is often families who are experiencing more difficulties who consent to participate in research. Without sampling the entire population of healthy siblings of children with cancer (which would clearly be impossible due to an individual's right to consent and withdrawal) it would not be possible to identify the extent to which there was a selection bias within the research. Thus due to the potential for selection bias, clearly caution is required in the acceptance of any findings/conclusions and clinical implications made from the data of the present study.

#### **4.2.3 Response Rate**

The response rate for the oncology group was 24.3% and 10.3% for the control group. This response rate was in line with typical response rates for postal questionnaires. (Breakwell et al. (1995) reported that response rates for postal questionnaires range from ten to forty percent). Whilst strategies were put in place to reduce the risk of non-participation (e.g. informed consent, confidentiality and anonymity), approximately only one-quarter of the healthy sibling of children with cancer population participated in the research. This leads to potential selection bias and thus a limit in the extent to which the study's results can be generalised.

Future research could examine whether there were specific demographic factors (e.g. socio-economic status, age/gender of healthy sibling etc.), methodological factors (e.g. nature/length of questionnaires etc.) or personal factors (e.g. exams, demands of treatment or denial or avoidance) that were reasons for individuals' non-participation. Previous research (not specifically focused on childhood cancer literature) has identified a number of different reasons for why individuals chose not to participate in research studies, including: questionnaires being too long, unfamiliar language and the personal nature/sensitivity of the questions (Fitzpatrick, Davey, Buxton & Jones, 1998). The Medical Research Council (1995) also identified that individuals may not participate in research due to psychological, physical, cognitive and sensory difficulties. Future research could be undertaken to explore strategies which could be put in place to increase potential participation rates (e.g. shorter/less questionnaires, information packs being distributed/administered at the oncology

clinic, follow-up reminder letters or medical staff informing the families about the research).

#### **4.2.4 Postal Questionnaires**

The methodological design of the present study involved participants completing and returning postal questionnaires. This design is typically associated with low response rates (Breakwell et al. 1995). However, the paper and pencil nature of a postal questionnaire is useful as it is not as financially expensive or as time and labour-intensive as face-to-face interviews. Additionally, it is often a useful means of obtaining information that an individual may not wish to disclose to an interviewer. However, the nature of postal questionnaires is such that there is no opportunity for participants to ask for clarification of any questions/issues they may not understand. Likewise, with postal questionnaires it is also not possible to ensure that the identified person is the one who actually completed the questionnaires without the assistance of others (e.g. in the present study it can not be guaranteed that parents did not assist the healthy siblings in the completion of the questionnaires). In future research into the impact of childhood cancer on healthy siblings, direct interviews with participants could be undertaken to identify if comparable results (to the postal questionnaires) are obtained and to examine if there is an increase in participation response rates. There have been inconsistent findings regarding which method (i.e. direct interviews or postal questionnaires) produces the most accurate and reliable information (Korner Bitensky, Wood, Dauphinee, Siemiatycki, Shapiro & Becker, 1994; Wilkund, Diemenas & Wahl, 1990). Whilst face-to-face interviews would allow for clarification (not possible with postal questionnaires) interviews are themselves not without potential difficulties (e.g. social acquiescence, situational pressure and interviewer effects) (Breakwell et al. (1995).

#### **4.2.5 Heterogenous Sample**

Due to the limited accessibility to participants and a small sample size, participants in this study were somewhat heterogeneous (as shown by the wide age range of healthy siblings, the disparity in marital/socio-economic statuses and the diversity of the illness characteristics of the ill siblings). Speechly & Noh (1992) emphasised the

way in which a heterogeneous sample can obscure and mask the real effects of childhood cancer on healthy siblings.

The ages of healthy siblings in the oncology group ranged from 8 to 16 years. Such age ranges spans middle childhood and adolescence. Individuals of these periods of development have different levels of cognitive understanding (Piaget, 1966) as well as developmentally different conceptualisations and understandings of illness/disease (Bibace & Walsh, 1980). Thus, rather than combining children of the different stages of development and treating them as a homogenous group (as was done in the present study) future research should focus on the extent to which specific difficulties are characteristic of the different age groups. Such research would require a larger number of healthy siblings in the different age groups than it were possible to obtain within the present study.

No data was collected on the siblings of participants in the control group. Thus, it was not possible to identify if factors such as birth order, family size and sibling combinations has a significant impact on the functioning of healthy siblings. It would thus be useful for future research to explore the extent to which compared with a control group healthy siblings of children with cancer are affected by such factors.

## **STRENGTHS OF THE RESEARCH**

Whilst it is acknowledged that there are a number of limitations in the methodology and design of the present research, there are also a number of significant strengths of the study. The present research extends on previous research in a number of ways:

### **4.2.6 Control Group**

Previous studies into the psychological effect of childhood cancer have tended to use either single-group designs, case-studies or compared the participant data to the normative data provided with the measures (see section 1.10). However, comparing the scores of healthy siblings of children with cancer with normative data can lead to an over-estimation of the difficulties experienced by this population (Sharpe & Rossiter 2002). Houtzager et al. (1999) maintained that healthy siblings of children with cancer should be compared with a control group as this gives a more accurate and valid representation of the actual level of their functioning and adjustment. Without a control group it would be difficult to conclude whether the difficulties experienced by healthy siblings of children with cancer is due to the cancer or is a by-product of childhood/adolescence. Thus the use of a control group should be viewed as being a major strength of the present study.

### **4.2.7 Standardised Measures/Checklists**

Previous studies have often used measures initially standardised on a different population which are then adapted/modified for use with children/adolescents (see section 1.10). This results in children/adolescents being asked to complete measures that may not be developmentally appropriate for their specific age groups. This usage of unstandardised measures has limited researchers in the extent to which they can argue that their measures and findings are valid/reliable. With the exception of the demographic questionnaire (which was used to obtain background information from parents) all measures/questionnaires employed in the present study had been previously for use with children/adolescents. The use of developmentally appropriate and standardised measures is viewed as a significant strength of the present research.



#### **4.2.8 Healthy Sibling Involvement**

Previous research into the effects of childhood cancer on healthy siblings has typically relied solely on parental reports (as discussed in section 1.8). Whilst it is acknowledged that parents are a very important source of information regarding the healthy sibling, it is unfortunate that this has resulted in a tendency to not involve the healthy siblings themselves. Particularly, in light of Walker's (1988) findings of forty-four percent disagreement between parents and healthy siblings regarding the impact of cancer on the healthy siblings. In the design of the present study it was recognised that healthy siblings were an important potential source of information regarding the impact which their brother's/sister's cancer had on them. Involving healthy siblings as participants is a strength of the present research, particularly due to the fact that it provided a forum for individuals whose voices frequently remain unheard.

#### **4.2.9 Number of Research Sites**

The relatively low prevalence of childhood cancer limited the number of individuals who would meet the inclusion criteria to participate in the research. Thus, it was recognised that to obtain a sufficient sample size it would be necessary to recruit participants from more than one Paediatric Oncology Department. Hence, the design of the study involved the Paediatric Oncology Services of NHS Lothian and NHS Tayside. As Williams (1997) identified, data collection from more than one paediatric oncology department not only ensures that the sample is a better representation of the population, but it also allows for greater generalisation of the research findings.

### **4.3 CLINICAL IMPLICATIONS & RECOMMENDATIONS**

Families are made up of a web of complex interactions, relationships and dynamics unique to that particular family unit. Thus, it is imperative that the multi-disciplinary team have an understanding of the potential implications that the diagnosis can have not only on the ill child/adolescent, but on the family as a whole. From the anecdotal information obtained from medical staff and families the undertaking of this research appears to have acted as a catalyst for increasing their awareness that healthy siblings of children with cancer are at a potential risk of developing difficulties as a result of the cancer diagnosis. The undertaking of this research offered health professionals, parents and healthy siblings themselves with a context and opportunity to consider the potential magnitude of the difficulties faced and encountered by this population. Anecdotally, during the time period of the research seven healthy siblings of children with cancer were referred to the Child & Adolescent Clinical Psychology Department of NHS Tayside. This is compared with no such referrals being made prior to the research being undertaken.

For many families the diagnosis of childhood cancer threatens the very foundations on which the family is built. With frequent periods of hospitalisation and clinic visits the ill child/adolescent, their parents and health professionals increasingly find their time, attention and resources focused on making the child/adolescent better. With the increased attention paid to the ill sibling, healthy siblings are often at risk of having unmet needs. Not only are healthy siblings faced with their siblings' illness, but also other domains of their life (e.g. peers and school etc.) continue to challenge them and their development. Based on the undertaking and findings of the present study, a number of implications for future clinical practices have been identified.

It is recognised that the following interventions may not be necessary, appropriate or desirable for all healthy siblings of children with cancer. However, it is argued that a significant number of healthy siblings do experience difficulties that should be a

target for intervention by members of the multi-disciplinary team responsible for the care of the ill child/adolescent.

#### **4.3.1 Monitoring & Early Prevention**

With the finding that healthy siblings of children with cancer are at a potentially increased risk of developing difficulties it is vitally important that clinicians monitor and assess the entire family unit. Relying on parents as the sole source of information regarding how the family is managing is insufficient. Assessments of the family of a child/adolescent with cancer need to involve all family members (including healthy siblings). Comprehensive developmentally age appropriate assessments are important in establishing the current functioning and adjustment of the different members of the family unit. Assessments of family functioning at the diagnosis stage only are insufficient. Regular monitoring and assessment of the family is necessary throughout the course of treatment and beyond. As Verte et al. (2003) identified, the effects of childhood cancer on healthy siblings are not uni-dimensional, but are associated with different reactions and effects at different developmental ages and stages in time. By undertaking regular assessment and monitoring it would be possible to identify those individuals who are experiencing or are at particular risk of developing difficulties. This would allow for the implementation of early intervention strategies to manage potential difficulties and to ensure that such difficulties do not escalate in severity and deleterious effect.

#### **4.3.2 Multi-Disciplinary Working**

A multi-disciplinary team approach is important in the care and management of a family where a child/adolescent has been diagnosed with cancer. Having different professionals working together enables the opportunity for both the physical, psychological and psychosocial domains of the family's life to be addressed as necessary. Ensuring that there is collaboration, co-ordination and communication within the team allows for the holistic needs of the family to be effectively and adaptively met and managed.

### **4.3.3 Types of Intervention**

Within the present study, healthy siblings of children with cancer were found to be experiencing significantly more difficulties relative to a control group. Likewise parents in the oncology group had statistically significantly higher scores on the Beck Depression Inventory-II than a control group. Whilst these findings should alert health professionals to the potential difficulties which may be experienced by families of children/adolescents with cancer, it is recognised that not all families will experience such negative sequelae. As discussed above, regular assessment and monitoring will enable the identification of those individuals/families who are experiencing difficulties. From this individualised assessment of the needs of the family, if considered appropriate, individualised interventions can be tailored to address the difficulties addressed by the healthy siblings. The form of the interventions should be structured depending on the symptoms exhibited by the individuals. For some educational one-off consultations with an emphasis on their pre-existing strengths and coping strategies may be sufficient in equipping them with the skills required to deal with their difficulties. However a more structured and supportive intervention may be required for others.

In such situations where it was considered necessary to intervene to help a healthy sibling of children with cancer, various factors should be taken into consideration. Timing of an intervention should be determined by the functioning of and the nature of the difficulties experienced by the healthy sibling and their family. Any intervention undertaken with a healthy sibling of a child with cancer should be appropriate to their age and developmental level. Whilst for some an information sheet/booklet regarding their sibling's illness may be sufficient, for others a more intensive intervention, such as a group, may be more appropriate.

#### **a.) Information Booklets**

Van Dongen-Melman et al. (1995) devised an information booklet for parents of a child with cancer. However, there is a lack of research regarding the efficacy of such approaches with healthy siblings of children with cancer. Age-appropriate information booklets could be developed for healthy siblings informing them about

the different aspects of their sibling's illness (e.g. the type of cancer and what will be involved in the treatment). The development of child/adolescent friendly information booklets would be useful in providing information to the healthy sibling in an age-appropriate, relaxed and informative way. The booklets would aim to reduce the healthy sibling's concerns and to promote their psychological wellbeing.

### **b.) Group Interventions**

A number of previous studies have examined the efficacy of group interventions for healthy siblings of children with cancer (Barrera, Chung, Greenberg & Fleming, 2002; Kinrade, 1985; Wamboldt & Wamboldt, 2000). Such interventions are typically effective in increasing the healthy siblings' knowledge of cancer and are normally positively rated by healthy siblings and their parents. However, many of these groups have been fairly unstructured, ran on an ad-hoc basis and for a very limited amount of time (e.g. in some cases the group ran for one day only). Despite such limitations of previous research into groups for this population, it is important to recognise the potential benefits that could be obtained from the implementation of a structured group. For example, groups could potentially produce an increase in healthy siblings' knowledge of illness/treatment procedures and allow for the facilitation of communication/expression of emotions. Healthy siblings may additionally benefit from the normalisation and socialisation opportunities inherent within such a group framework.

Recognising the psychological and behavioural difficulties experienced by healthy siblings of children with cancer it is argued that it would be beneficial for future research to systematically evaluate the potential efficacy of interventions with this population.

## **4.4 FUTURE RESEARCH**

A number of potential areas for future research have already been explored above, however from the undertaking and results of the present study a number of further areas for future research have been identified:

### **4.4.1 Longitudinal Study**

Due to the time-limited nature of the research it was not possible to undertake a longitudinal study into the psychological effects of childhood cancer on healthy siblings. Whilst there are a number of difficulties associated with longitudinal research (e.g. labour and time intensive, financially expensive and a high risk of attrition) (Breakwell et. al., 1995) undertaking such research would enable the identification of the long-term developmental consequences of cancer on healthy siblings. A longitudinal study would allow the identification of fluctuations or trends in the adjustment and functioning of healthy siblings throughout the course of their ill sibling's diagnosis and treatment. Such research would be useful in identifying if there were any particular stages during the treatment process where the healthy sibling may be at an increased risk of developing difficulties (e.g. post-diagnosis, during treatment, at remission or relapse). Longitudinal studies would also enable researchers and clinicians to identify if the impact of the cancer on healthy siblings is a short-term consequence of the diagnosis, or if the difficulties experienced by healthy siblings are perpetuated over the long-term.

### **4.4.2 Effect of Background Factors**

Within the context of the present study a number of background factors that may potentially increase the difficulties experienced by healthy siblings of children with cancer were not explored. Thus, future research could examine whether the following factors impact on healthy siblings' adjustment post-diagnosis: family size, birth order, age/gender of ill sibling, sibling combinations, level of healthy sibling knowledge regarding the cancer, visibility of the cancer (i.e. amputation), culture/ethnicity of the family, personality, temperament and self-esteem of healthy siblings and premorbid functioning of the family/healthy sibling.



#### **4.4.3 Impact on Younger Healthy Siblings**

Due to the recognition that there was a need for standardised measures to be employed in the present study healthy siblings younger than eight years were excluded from the data. This age criteria were selected as it was not considered appropriate to use measures that were not developmentally appropriate for children under eight years. Despite this, it is recognised that regardless of their age healthy siblings are likely to experience some effect as a result of their sibling's illness. Thus, an area for future research would be to explore alternative ways in which the psychological effects of childhood cancer on healthy siblings under eight years could be assessed and explored (e.g. via the development of standardised age-appropriate measures, the use of play therapy, puppets and direct observations of behaviour).

#### **4.4.4 Coping & Resilience in Healthy Siblings**

The results of the present study indicated that many healthy siblings of children experience psychological and behavioural difficulties as a consequence of their sibling's cancer. Although not studied within the confines of the present research, it is however, recognised that there may be positive sequelae for healthy siblings of children with cancer. As Houtzager et al. (1999) identified, coping is a mediating variable between the diagnosis of cancer and the healthy sibling's adaptation to it. By looking at issues such as the resilience of and the coping strategies employed by healthy siblings of children with cancer it may be possible to develop a psychological model describing how psychological functioning can be facilitated and coping strategies developed in those healthy siblings who do experience psychological difficulties as a consequence of their sibling's cancer diagnosis.

#### **4.4.5 Qualitative Research**

The design of the present study was quantitative. However, with regards to future research it is argued that a qualitative approach would be a useful methodological approach. Qualitatively exploring the meanings and experiences of healthy siblings of children with cancer would allow for a more detailed and comprehensive description and account to be obtained.

## 4.5 CONCLUSIONS

The aim of the present study was to investigate the impact of childhood cancer on healthy siblings. The present research found that healthy siblings of children with cancer exhibited significantly more psychological difficulties than a control group. However there were no significant differences between the two groups in the level of their behaviour problems. Parents in the oncology group were also found to be exhibiting more depressive symptomatology than did parents in the control group. Male siblings and siblings over the age of thirteen years, in the oncology group, were found to display significantly more behaviour problems than females and under 12s in the oncology group and all participants in the control group.

Parents and healthy siblings were found to agree regarding the impact that the cancer had on healthy siblings. Healthy siblings' scores on the Behaviour Problem and Social Competence scale of the Child Behaviour Checklist were found to be significant variables that were predictive of parental depression.

Based on the significant level of psychological difficulties found in healthy siblings of children with cancer it is argued that a number of clinical interventions can should be developed and evaluated (i.e. one-to-one interventions, information leaflets and group work). Future research should focus on the undertaking of longitudinal studies in order to identify the developmental effects of cancer on healthy siblings. Additionally, future research should focus on exploring coping/resilience in healthy siblings and the impact of childhood cancer on younger healthy siblings.

## **CHAPTER FIVE - REFERENCES**

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## **CHAPTER SIX – APPENDICES**



## APPENDICES

<b>Appendix Number</b>	<b>Description of Appendix</b>
<b>1</b>	<b>Letter confirming that ethical approval was granted from Tayside Committee on Medical Research Ethics and the Lothian Paediatrics/Reproductive Medicine Research Ethics Committee</b>
<b>2</b>	<b>Initial letters sent to participants</b>
<b>3</b>	<b>Information sheets for participants</b>
<b>4</b>	<b>Parent/guardian completed questionnaires/measures</b> a.) Demographic Questionnaire b.) Child Behaviour Checklist (Achenbach, 1991) c.) Beck Depression Inventory (Beck et al. 1986) d.) Sibling Perception Questionnaire (Taylor et al. 2001)
<b>5</b>	<b>Child/adolescent completed questionnaires/measures</b> a.) Child Depression Inventory (Kovacs, 1985) b.) Sibling Perception Questionnaire (Carpenter & Sahler, 1991)
<b>6</b>	<b>Definition of the National Statistics Socio-Economic Classification Definitions (NS-SEC)</b>
<b>7</b>	<b>Guidelines for interpreting the T-Scores of the Child Depression Inventory (Kovacs, 1985)</b>
<b>8</b>	<b>Descriptive &amp; statistical analysis of the data</b>

<b>Appendix 1</b>	<b>Letter confirming that ethical approval was granted from Tayside Committee on Medical Research Ethics and the Lothian Paediatrics/Reproductive Medicine Research Ethics Committee</b>
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Direct Line 0131 536 9022  
Email [joyce.clearie@lhb.scot.nhs.uk](mailto:joyce.clearie@lhb.scot.nhs.uk)  
US IRB No.: IRB00001462

Dear Miss MacLeod,

### COMING OUT OF THE SHADOWS: THE IMPACT OF CHILDHOOD CANCER ON HEALTHY SIBLINGS.

Thank you for submitting the above research proposal for ethical review. The Paediatrics/Reproductive Medicine Research Ethics Committee of the Lothian Research Ethics Committee has reviewed this proposed research and has given it a favourable ethical opinion. An official Certificate of Ethical Opinion outlining the conditions of this opinion is enclosed together with a list of members present at the meeting. Please note that the LREC reference number LREC/2004/6/8 **must** be quoted on all correspondence. Correspondence received without the LREC reference number will be returned.

Under the terms of the Scottish Executive Health Department Research Governance Framework for Health and Community Care this opinion has been notified to the Research & Development Office of the relevant NHS Trust(s) where the research is intended to take place. It is the NHS Trust(s) from whom you must obtain management approval before any work on the proposed research can proceed.

Details of the Lothian Research Ethics Committee and its documentation can be found on [http://www.nhslothian.scot.nhs.uk/nhs\\_lothian/about\\_lothian\\_health/lrec/index.html](http://www.nhslothian.scot.nhs.uk/nhs_lothian/about_lothian_health/lrec/index.html)

Yours sincerely



Headquarters  
Deaconess House 148 Pleasance Edinburgh EH8 9RS

Chair Brian Cavanagh  
Chief Executive James Barbour O.B.E.  
*Lothian NHS Board is the common name of Lothian Health Board*

## LOTHIAN RESEARCH ETHICS COMMITTEE

### CERTIFICATE OF ETHICAL OPINION

LREC Reference Number: LREC/2004/6/8

Title: Coming out of the Shadows: The Impact of Childhood Cancer on Healthy Siblings.

Researcher: Miss Fiona MacLeod

The Paediatrics/Reproductive Medicine Research Ethics Committee of the Lothian Research Ethics Committee (the Committee) reviewed this proposed research and is of the opinion that it is ethical and appropriate to be carried out in the Lothian Area. This opinion encompasses all aspects of the application including the Patient/Subject Information Sheet and all other accompanying documentation provided.

The LREC application form, protocol, subject information sheet, information on compensation arrangements, payments to researchers and the provision of expenses to subjects (where appropriate) were reviewed and approved and the members of the Committee present at the meeting are shown on the attached *Membership List*.

This opinion is issued subject to the following conditions and is invalid if they are not followed:

- You must obtain appropriate management approval from the relevant NHS Trust(s) before starting the proposed research. It is the NHS Trust(s) that ultimately decide whether or not this research should go ahead taking account of the advice of the Local Research Ethics Committee.
- You must notify the Sub-Committee and the relevant NHS Trust(s), in advance, of any significant proposed deviation from the original protocol or application form and obtain approval for any such amendments using the *Amendment Approval Request Form*.
- You must submit reports to the Sub-Committee and the NHS Trust(s) once the study is underway if there are any unusual or unexpected results which raise questions about the safety of the research.
- You must report annually on successes, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the study among patients and volunteers using the *Progress Report Form*.
- Where the study is terminated prematurely you must report within fifteen days indicating the reasons for early termination..
- You must submit a final report within three months of the completion of the study using the *Progress Report Form*.

**Peter Reith**  
Secretary  
Lothian Research Ethics Committee

**Joyce Clearie**  
Administrator  
Paediatrics/Reproductive Medicine  
Research Ethics Committee

28 April 2004



Ms Fiona J Macleod  
Trainee Clinical Psychologist  
Tayside Area Clinical Psychology Department  
Child & Adolescent Psychology  
19 Dudhope Terrace  
DUNDEE DD3 6HH

Date 20 February 2004  
Your Ref  
Our Ref NFB/FB/017/04  
Enquiries to Mr Nigel F Brown  
Extension 32701  
Direct Line 01382 632701  
Email [nigel.brown@tuht.scot.nhs.uk](mailto:nigel.brown@tuht.scot.nhs.uk)  
or  
[fiona.bain@tuht.scot.nhs.uk](mailto:fiona.bain@tuht.scot.nhs.uk)

### Initial Response Form for Applicants

**Reference Number:** 017/04

**Title of Proposal:** Coming out of the shadows: The impact of childhood cancer on healthy siblings

**First Researcher:** Ms F J Macleod, Trainee Clinical Psychologist, Child & Adolescent Psychology Department

**Documentation Reviewed:**

Proposal Form  
Subject Consent Form(s)  
Subject Information Sheet(s), versions 2, dated 22 January 2004  
Questionnaire(s)

**REVIEW OUTCOME:** APPROVED

**This application has been considered and the Tayside Committee on Medical Research Ethics would like to make the following comments:**

The latter part of the postcode (last letters) should be removed from the questionnaire as this comes close to being an identifier.

**Conditions of Approval:**

- The research may proceed only when you are also in possession of a final approval letter from the NHS Tayside R & D to whom I am copying this letter.
- You should follow the protocol agreed and advise the Committee of any proposed amendments – no significant changes to the protocol should be made without Ethics Committee approval.
- You must promptly inform the Ethics Committee of deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subject; of any changes that increase the risk to subjects and/or affect significantly the conduct of the research; all adverse events that are both serious and unexpected; new information that may adversely affect the safety of the subjects or the conduct of the research; if the research is abandoned for any reason.
- Each research proposal will be subject to a follow-up review and may be selected for a monitoring visit on behalf of the Tayside Trusts.
- You must start the project within three years of the date approval is given or the approval expires; extensions can be applied for.



Members: Dr J Davidson (Chairman); Mr P K Brown; Ms D Campbell (Vice Chairperson); Dr C Jackson; Dr F Daly; Mr A S Jain; Miss E S Macallan; Dr S MacAndrew; Mr A MacConnachie (Medical Advisor); Mr G MacLaren; Dr W Stevenson; Dr M A R Thomson; Mrs F Valentine; Mrs L Van Aalten.  
Deputies: Dr D Cuthbertson; Dr E Mitchell; Ms M Paterson; Dr D Carson  
Administrator: Mr N F Brown

- You are required to provide an annual update on the progress of the study and notify the Committee of its termination.

***Date of Review:*** 30 January 2004

***List of Members in attendance:*** Dr J Davidson; Mrs D Campbell; Dr F Daly; Mr A S Jain; Dr S MacAndrew; Mr A M MacConnachie; Mr T McEwan; Mr G MacLaren; Dr E Mitchell; Dr M A R Thomson; Mrs F Valentine

It would be helpful if in the event of there being any future correspondence about this study, you could quote Ref: 017/04

***Signed***

^

**Nigel F Brown**

**LREC ADMINISTRATOR**

***On behalf of the Tayside Committee on Medical Research Ethics***

cc: Mrs K Coll, NHS Tayside R & D



<b>Appendix 2</b>	<b>Initial letters sent to participants</b>
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Dear Parent(s)/Guardian(s)

### **Research Project on the Impact of Illness on Healthy Siblings**

We are writing to inform you about a research project that is currently taking place in conjunction with NHS Tayside and NHS Lothian. The Paediatric Oncology Services in Dundee and Edinburgh are presently undertaking research into the impact which childhood cancer/leukaemia can have on the healthy brothers and sisters in the family. From what other families have told us we are aware that cancer/leukaemia can have a major impact on the rest of the siblings in the family. Despite families' and health professionals' awareness of the impact of the illness on healthy siblings it remains an area which is under researched within the literature.

In this research project we are interested to find out more about the thoughts, feelings and experiences of children and adolescents (aged 8 to 17 years) whose brother or sister has/or has had cancer/leukaemia. By researching the effect of the illness on the rest of the children in the family we are hoping to identify ways in which we can help siblings in the future whose brother or sister is diagnosed with cancer/leukaemia.

In order to let you know more about the research, we have enclosed an information sheet providing more details regarding the present project. Participation in the research project is entirely voluntary and you and your family do not have to participate in the research if you do not want to. However if you do wish to take part in the research project we would be grateful if you could complete the enclosed questionnaires. The questionnaires are to be completed both by parent(s)/guardian(s) and by the healthy siblings (aged 8 to 17 years). The questionnaires will help us find out more about the effects of the illness on healthy brothers and sisters. If you decide to participate in the research project we have enclosed a stamped addressed envelope so that you can return the completed questionnaires to us at the department.

If you have any queries regarding the research please do not hesitate to contact us.

Yours sincerely

**Fiona J Macleod**  
**Trainee Clinical Psychologist with**  
**Joyce Davies**  
**Consultant Clinical Child Psychologist**

**Consultant Paediatrician**

Department of Clinical Psychology  
Centre for Child Health  
19 Dudhope Terrace  
Dundee DD3 6HH  
(01382) 346565

**Lothian University  
Hospital Trust  
Tayside Primary Care**

*Tayside Area Clinical Psychology Department  
Child & Adolescent Clinical Psychology  
Centre for Child Health  
19 Dudhope Terrace  
DUNDEE  
DD3 6HH  
Telephone Number: 01382 346565  
Fax Number: 01382 346555  
Email: [fiona.j.macleod@tpct.scot.nhs.uk](mailto:fiona.j.macleod@tpct.scot.nhs.uk)*



Dear Parent(s)/Guardian(s)

Please find enclosed information about a research project that is currently being run by the Child & Adolescent Clinical Psychology Department and the Paediatric Oncology Departments of NHS Lothian and NHS Tayside. We are wanting to investigate the experiences of siblings of children with cancer and compare them with a group of children/adolescents who has a sibling without cancer. Staff at Primary School and High School have kindly agreed to be involved in the research and have agreed to distribute the questionnaires to pupils within the schools.

We have enclosed an information leaflet that outlines more information regarding the research. If you wish to participate in the research we would ask that you and your son/daughter complete the enclosed questionnaires and return them either by posting them in the enclosed stamped addressed envelope or by returning them to the school. If you agree to participate in the research project you would not be required to provide us with any personal information such as your name, address or your child's name. All the information you give us will be completely private and confidential.

You do not have to participate in the research, however if you did wish to participate your participation would be greatly appreciated.

If you have any queries regarding the project please do not hesitate to contact me at the department.

Yours sincerely

**Fiona J Macleod  
Trainee Clinical Psychologist with  
Joyce Davies  
Consultant Clinical Child Psychologist**

Headquarters  
Ashludie Hospital, Monifieth, Angus, DD5 4HQ

Chairperson, Mr Murray Petrie  
Head of Services, Mr Daniel McLaren  
*Tayside NHS Board is the common name of Tayside Health Board*



<b>Appendix 3</b>	<b>Information sheets for participants</b>
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## **Oncology Group**

**The Impact of Illness on Healthy Brothers & Sisters  
Project Information Sheet for Parents/Guardians**

We would like to invite you to participate in a research project we are currently undertaking in the hospital. We believe it to be of potential importance. However, before you decide whether or not you wish to participate, we need to ensure that you understand firstly why we are doing the project, and secondly what would be involved if you agreed to take part in the project. We are therefore providing you with the following information about the project.

- ***The Background to the Study***

- We are interested in finding out about the effect on children and adolescents of having a brother or sister who has cancer/leukaemia.
- We recognise that having a brother or sister with cancer/leukaemia can have a huge impact on someone and we are interested in finding out what that impact is.
- We are interested to find out how, children and teenagers, whose brother or sister is unwell, feel and think about things.
- The research is being undertaken in conjunction with the Paediatric Oncology Department, NHS Tayside and the Haematology & Oncology Department, NHS Lothian
- 80 other families have been asked to consider participating in the project.

- ***What does the study entail?***

- If you decide to take part in the project we would ask you to complete the enclosed questionnaires.
- It would take approximately 20-30 minutes to complete all the questionnaires in the envelope
- As we are just asking you to complete some questionnaires, there will be no side-effects or risk associated with participating in this study. However, if you find some of the questions make you upset or distressed you don't have to complete them. If you wish to discuss any issues regarding the research you can contact us at the numbers at the bottom of this information sheet.

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Chairperson, Mr Murray Petrie  
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- ***The contents of the questionnaires***
  - The questionnaires to be completed by parents/carers include the following;
    - a background questionnaire (e.g. the healthy sibling's age, your marital status and occupation etc.)
    - a questionnaire about your thoughts and feelings over the past two weeks
    - a checklist about the healthy sibling's general behaviour over the past six months
    - a questionnaire about your beliefs about how your healthy child perceives their sibling's illness
  - The questionnaires to be completed by the healthy siblings include the following;
    - A questionnaire about their thoughts and feelings over the past two weeks
    - A questionnaire about their perceptions of their sibling's illness
- ***What will happen to the information collected in the study?***
  - After completing the questionnaires we would request that you return them, in the enclosed stamped-addressed envelope. We have enclosed extra stamped-addressed envelopes so that if they want to your healthy children can return their questionnaires separately.
  - By you returning the questionnaires to us we will presume that you have given your consent to take part in this project.
  - The information you provide us with will be entirely private and confidential.
  - The data you provide us with will be stored in a secure location (e.g. in a locked filing cabinet). The data will be stored on a password protected computer file. Only the researchers would have access to the information.
- ***What are my rights?***
  - Participation in this study is entirely voluntary and you are entirely within your rights not to participate in this study. You are free to withdraw from this study at any time without having to provide a reason. If you want you are very welcome to discuss this with other people (e.g. friends or relatives etc.) before deciding whether or not to participate
- ***What Will Happen After the Study?***
  - Once all the data is collected and if you would like to hear about the findings of the project, the researchers would be happy to meet with the people who participated in the research to discuss the outcome of the research.
  - It is important to acknowledge that the questionnaires involve questions about people's thoughts and feelings about themselves and their family. You might find some the questions upsetting or distressing, if this is the case please do not hesitate to contact us at the numbers at the bottom of this information sheet.

Participation in this study is entirely voluntary and you are free to refuse to take part or withdraw from the study at any time without having to give a reason and without this

affecting your future medical care or your relationship with medical staff looking after you and your family. Both the Lothian and the Tayside Committees on Medical Research Ethics, which have responsibility for scrutinising all proposals for medical research on humans in Lothian and Tayside, have examined the proposal and have raised no objections from the point of view of medical ethics.

If you wish more information or have any queries regarding this project please contact:

Fiona J Macleod  
Trainee Clinical Psychologist  
Department of Clinical Psychology  
19 Dudhope Terrace  
Dundee DD3 6HH  
(01382) 346565  
[fiona.j.macleod@tpct.scot.nhs.uk](mailto:fiona.j.macleod@tpct.scot.nhs.uk)

*Local Adviser:*

Dr Paul Morris  
Lecturer in Health Psychology  
University of Edinburgh  
Kennedy Tower  
Royal Edinburgh Hospital  
Edinburgh EH10 5HF  
(0131) 537 6416

*Contact Details:*

NHS Lothian  
Haematology & Oncology Dept  
Royal Hospital for Sick Children  
Sciennes Road  
Edinburgh EH9 1LF  
(0131) 536 0420

NHS Tayside  
Paediatric Oncology Department  
Ninewells Hospital & Medical  
School  
Dundee  
(01382) 660111

**The Impact of Illness on Healthy Brothers & Sisters  
Project Information Sheet for Thirteen Years & Over**

- We are currently undertaking research in the hospital at the moment and we were wondering if you would like to participate in it. The following information sheet describes what would be involved if you took part in the research.
- We are aware that having a brother or sister who is ill can have a huge impact on the whole family. We are interested to find out what it is like for boys and girls who have a brother or sister who is ill.
- If you decide to take part in the research we would ask you to complete the attached questionnaires. There are two questionnaires that we would like you to fill out. One is to find out more about your thoughts and feelings over the past two weeks and the other one is to find out what you think about having a brother or sister who is ill.
- The questionnaires are not a test and all the information you give us is entirely confidential and private. We will not be able to identify who filled out what questionnaire. The questionnaires would take about fifteen to twenty minutes to complete.
- We are aware that you might not want your parents/guardians to read your responses to the questionnaires so we have enclosed a stamped – addressed envelope for you to return your questionnaires in and a stamped – addressed envelope for your parents/guardians to return their measures in. However if you chose feel free to return all the questionnaires in the same envelope.
- You do not have to participate in the research if you do not want to. If you decide that you want to take part in the research but change your mind later that is ok. If you decide that you do not want to participate in the research the doctors and nurses who look after your brother or sister will not treat them or your family any differently.
- Your parents/guardians have been advised about the research and you should feel free to speak to them about the research.

**What it is like to have a brother or sister who is unwell?  
Information Sheet for Twelve Years & Under**

- We were wondering if you would like to take part in a project we are doing in the hospital at the moment. The following information is given to help you decide if you would like to take part in the project.
- The aim of this project is to find out what it is like for people who have a brother or sister who is unwell. We want to find out what boys and girls, like you, feel and think about different things.
- If you decide to take part in the project we would ask you to fill out two questionnaires about yourself and your family. The questionnaires would take about 20 minutes to complete.
- All the information that you give us will be private.
- You can decide whether or not you want to take part. You don't have to take part if you don't want to.
- If you do decide that you would like to take part in the research, it is important that you remember that even if you say yes now it is ok for you to change your mind later and say no. No one will mind if you decide you don't want to carry on with the project.
- If you chose not to take part, this will not make any difference to the way the doctors and nurses look after you or your family. Your parents/guardians have been told all about the project and you can talk to them about it. If you would like to talk to the staff at the hospital about the project that is ok too.

**Control Group**

**The Impact of Illness on Healthy Brothers & Sisters  
Information Sheet for Parents/Guardians**

We would like to invite you to participate in a research project that we are currently undertaking in the department. However, before you decide whether or not to participate, we need to ensure that you understand firstly why we are doing the project, and secondly what would be involved if you agreed to take part in the project.

We are therefore providing you with the following information about the project.

Read the following information carefully, and, if you want you can discuss it with friends or families.

You do not have to make an immediate decision and you do not have to participate if you don't want to.

- **The Background to the Study**

- We are currently undertaking research at Ninewells Hospital to find out about the impact on children and adolescents whose brother or sister has cancer.
- For part of the project we are interested in comparing children and adolescents whose brother or sister has cancer with children and adolescents, like in your family, whose brother or sister is not unwell. We are interested to find out what children and adolescents, whose brother or sister is well, think and feel about different things.
- Other families at the school have been asked to consider participating in the study.

- **What Does They Study Entail?**

- If you decide to take part in the project you would be asked to complete the enclosed questionnaires
- It would take approximately twenty to thirty minutes to complete all the questionnaires.
- As we are just asking you to complete some questionnaires, there should be no side-effects or risks associated with participating in this project. However if you find some of the questions make you upset or distressed you don't have to complete them. If you wish to discuss any issues regarding the

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research you can contact me at the number at the bottom of this information sheet.

- **What will happen to the information collected in the study?**

- In order to protect your anonymity and protect your confidentiality we are not asking you to provide us with any identifying information such as your name or address etc.
- Rather after completing the enclosed questionnaires we would request that you either return them in the enclosed envelope to the school or post them to me at the department.
- By you returning the questionnaires to us we will presume that you have given your consent to take part in this project.
- The information you provide us with will be entirely private and confidential and because none of your personal details, such as your name or address etc., is contained on the questionnaires there is no way that anyone can know who completed the questionnaires.
- The data you provide us with will be stored in a secure location (e.g. in a locked filing cabinet). The data will be stored on a password protected computer file. Only the researchers would have access to the information.

- **What are my rights?**

- Participation in this study is entirely voluntary
- You are entirely within your rights not to participate in this study.
- You are free to withdraw from this study at any time without having to give a reason.
- If you want you are very welcome to discuss this with other people (e.g. friends or relatives etc.) before deciding whether you want to participate.

The Lothian and Tayside Committees on Medical Research Ethics, which have responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside and the Regulatory Authorities.

If you wish more information regarding this project please contact:

Fiona J Macleod  
Trainee Clinical Psychologist  
Department of Clinical Child Psychology  
19 Dudhope Terrace  
Dundee  
(01382) 346565  
[fiona.j.macleod@tpct.scot.nhs.uk](mailto:fiona.j.macleod@tpct.scot.nhs.uk)

**The Impact of Illness on Healthy Brothers & Sisters  
Project Information Sheet for Thirteen Years & Over**

- We want to tell you about a research project that is currently being undertaken by the Department of Clinical Psychology. The following information sheet describes what would be involved if you took part in the research.
- We are aware that having a brother or sister who is ill can have a huge impact on the whole family. We are interested to find out what it is like for boys and girls who have a brother or sister who is ill. However to help us do that we want to find out how people like you, whose brother/sister is not ill, think and feel about things.
- If you decide to take part in the research we would ask you to complete the attached questionnaire. The questionnaire is to find out more about your thoughts and feelings over the past two weeks
- The questionnaire would take about five to ten minutes to complete. The questionnaire is not a test and all the information you give us is entirely confidential and private. We will not be able to identify who filled out what questionnaire.
- We are aware that you might not want your parents/guardians to read your responses to the questionnaires so we have enclosed a stamped-addressed envelope for you to return your questionnaires in and a stamped-addressed envelope for your parents/guardians to return their measures in. However if you chose feel free to return all the questionnaires in the same envelope.
- You do not have to participate in the research if you do not want to. If you decide that you want to take part in the research but change your mind later that is ok.
- Your parents/guardians have been advised about the research and you should feel free to speak to them about the research.

**What is it like to have a brother or sister who is unwell?  
Information Sheet for Twelve Years & Under**

- We were wondering if you would like to take part in a project, which the Department of Clinical Psychology is carrying out at the moment. The following information is given to help you decide if you would like to take part in the project.
- We are trying to find out what it is like for boys and girls who have a brother or sister who is unwell. We want to find out how they feel and what they think about having a brother or sister whom is sick.
- We want to find out what boys and girls, like you, who don't have a brother or sister who is ill, feel and think about different things too.
- If you decide to take part in the project we would ask you some questions about yourself and your family.
- The project would take about 20 minutes to complete.
- All the information that you give us will be private.
- You can decide whether or not you want to take part.
- You don't have to take part if you don't want to.
- Even if you say yes now it is ok for you to change your mind and say no later.
- Your parents/guardians know about the project and you can talk to them about it.

<b>Appendix 4</b>	<b>Parent/guardian completed questionnaires/measures</b> e.) Demographic Questionnaire f.) Child Behaviour Checklist (Achenbach, 1991) g.) Beck Depression Inventory (Beck et al. 1986) h.) Sibling Perception Questionnaire (Taylor et al. 2001)
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## **The Impact of Illness on Healthy Brothers & Sisters Demographic Questionnaire**

Below are a number of questions about you and your family that we would ask you to complete.

### **About You**

- 1.) What is your relationship to the child/adolescent whom you are completing the measure about? (e.g. mother, father or guardian etc.) .....
- 2.) What is your marital status (e.g. single, married, separated, divorced, widowed, living with partner, other etc.)? .....
- 3.) What is your post code? (e.g. DD3 6HH) .....

### **About the Child/Adolescent Whom You Are Completing the Measures About**

- 4.) What is the age (in years) of the child/adolescent whom you are completing the measures about? .....years
- 5.) Is the child/adolescent? (please tick)  
Male (    )                      Female (    )

### **About Your family**

- 6.) What is the age of your child who has/had cancer? .....
- 7.) What is the gender of your child who has/had cancer (please tick)  
Male (    )                      Female (    )
- 8.) What diagnosis has/had your unwell child/adolescent been given?  
.....
- 9.) What type of treatment is/has your unwell child/adolescent receiving/received?  
.....
- 10.) How long has it been since the diagnosis was made? .....

*Thank You For Completing This Questionnaire*

## **The Impact of Illness on Healthy Brothers & Sisters Demographic Questionnaire**

Below are a number of questions about you and your family that we would ask you to complete and return to us with the rest of the completed measures.

- 1.) Does any of the children/adolescents in your immediate family have a long-term illness or disability (such as cancer, diabetes, cystic fibrosis, asthma, a learning disability, autism etc.)? Yes ( ☐ ) No ( ☐ )  
If yes, please specify illness .....

.....

### **About You**

- 2.) What is your relationship to the child/adolescent whom you are completing the measures about (e.g. mother, father or guardian etc.) .....
- 3.) What is your marital status? (e.g. single, married, separated, divorced, widowed, living with partner, other etc.)? .....
- 4.) What is your occupation? .....

### **About The Child/Adolescent Whom You Are Completing the Measures About**

- 5.) What is the age (in years) of the child/adolescent? .....years
- 6.) Is the child/adolescent? (please tick)  
Male ( ☐ ) Female ( ☐ )

*Thank you for completing this questionnaire*



Code \_\_\_\_\_

**Child Behaviour Checklist**

Please fill out this form to reflect *your* view of the child's behaviour even if other people might not agree. Feel free to print additional comments beside each item and in the spaces provided on page 2.

<b>I. Please list the sports your child most likes to take part in.</b> For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.	<b>Compared to others of the same age, about how much time does he/she spend in each?</b>				<b>Compared to others of the same age, how well does he/she do each one?</b>			
____ None	Don't Know	Less than Average	Average	More than Average	Don't Know	Below Average	Average	Above Average
a.)								
b.)								
c.)								
<b>II. Please list your child's favourite hobbies, activities and games, other than sports.</b> For example: stamps, dolls, books, piano, crafts, cars, singing, etc. (Do not include listening to radio or TV)	<b>Compared to others of the same age, about how much time does he/she spend in each?</b>				<b>Compared to others of the same age, how well does he/she do each one?</b>			
____ None	Don't Know	Less than Average	Average	More than Average	Don't Know	Below Average	Average	Above Average
a.)								
b.)								
c.)								
<b>III. Please list any organisations, clubs, teams or groups your child belongs to.</b>	<b>Compared to others of the same age, how active, is he/she in each?</b>							
____ None	Don't Know	Less Active	Average	More Active				
a.)								
b.)								
c.)								
<b>IV.) Please list any jobs or chores your child has.</b> For example: paper route, babysitting, making beds, working in store. (Include both paid and unpaid jobs and chores).	<b>Compared to others of the same age, how active, is he/she in each?</b>							
____ None	Don't Know	Less Active	Average	More Active				
a.)								
b.)								
c.)								

Code \_\_\_\_\_

V.) 1.) About how many close friends does your child have? (Do *not* include brothers & sisters)

( ) None ( ) 1 ( ) 2 or 3 ( ) 4 or more

2.) About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters)

( ) Less than 1 ( ) 1 or 2 ( ) 3 or more

VI.) Compared to others of his/her age, how well does your child:

	Worse	About Average	Better
a.) get along with his/her brothers & sisters?			
b.) get along with other kids?			
c.) behave with his/her parents?			
d.) play and work alone			

( ) Has No  
Brothers or  
Sisters

VII.) 1.) For ages 6 and older – Performance in Academic Subjects

( ) Does not attend school because \_\_\_\_\_

Check a box for each subject that the child takes		Failing	Below Average	Average	Above Average
Other academic subjects (computer, foreign languages, business)	a.) Reading, English or Language				
	b.) History or Social Studies				
	c.) Arithmetic or Math				
	d.) Science				
	e.)				
	f.)				
	g.)				

2.) Does your child receive special remedial services or attend a special class or special school?

( ) No ( ) Yes (please specify) \_\_\_\_\_

3.) Has your child repeated any grades?

( ) No ( ) Yes – please specify \_\_\_\_\_

4.) Has your child had any academic or other problems in school?

( ) No ( ) Yes – please specify \_\_\_\_\_

when did these problems start? \_\_\_\_\_

have these problems ended? ( ) No ( ) Yes

Does your child have any illness, physical disability, or learning disability?

( ) No ( ) Yes  
please specify \_\_\_\_\_

What concerns you most about your child?

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Please describe the best things about your child:

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Code \_\_\_\_\_

Below is a list of items that describe children and youth. For each item that describes your child **now or within the past 6 months**, please circle the 2 if the item is **very true** or **often true** of your child. Please circle the 1 if the item is **somewhat** or **sometimes true** of your child. If the item is not true of your child, circle the 0. Please answer all the items as well as you can, even if some do not seem to apply to your child.

**0 = Not True (as far as you know) 1 = Somewhat/Sometimes True 2 = Very True/Often True**

0	1	2	1.) acts too young for his/her age	0	1	2	31.) fears he/she might think or do something bad
0	1	2	2.) allergy (describe)	0	1	2	32.) feels he/she has to be perfect
0	1	2	3.) argues a lot	0	1	2	33.) feels or complains that no one loves him/her
0	1	2	4.) asthma	0	1	2	34.) feels others are out to get him/her
0	1	2	5.) behaves like opposite sex	0	1	2	35.) feels worthless or inferior
0	1	2	6.) bowel movements outside of toilet	0	1	2	36.) gets hurt a lot, accident – prone
0	1	2	7.) bragging, boasting	0	1	2	37.) gets in many fights
0	1	2	8.) can't concentrate, can't pay attention for long	0	1	2	38.) gets teased a lot
0	1	2	9.) can't get his/her mind off certain thoughts/obsessions (describe)	0	1	2	39.) hangs around with others who get into trouble
0	1	2	10.) can't sit still, restless, or hyperactive	0	1	2	40.) hears sounds or voices that aren't there (describe)
0	1	2	11.) clings to adults/too dependent	0	1	2	41.) impulsive/acts without thinking
0	1	2	12.) complains of loneliness	0	1	2	42.) would rather be alone than with others
0	1	2	13.) confused or seems to be in a fog	0	1	2	43.) lying or cheating
0	1	2	14.) cries a lot	0	1	2	44.) bites finger nails
0	1	2	15.) cruel to animals	0	1	2	45.) nervous, highstrung or tense
0	1	2	16.) cruelty, bullying, or meanness to others	0	1	2	46.) nervous movements or twitching (describe)
0	1	2	17.) day-dreams or gets lost in his/her thoughts	0	1	2	47.) nightmares
0	1	2	18.) deliberately self-harms or attempts suicide	0	1	2	48.) not liked by other kids
0	1	2	19.) demands a lot of attention	0	1	2	49.) constipated, not move bowels
0	1	2	20.) destroys his/her own things	0	1	2	50.) too fearful or anxious
0	1	2	21.) destroys things belonging to his/her family or others	0	1	2	51.) feels dizzy
0	1	2	22.) disobedient at home	0	1	2	52.) feels too guilty
0	1	2	23.) disobedient at school	0	1	2	53.) overeating
0	1	2	24.) doesn't eat well	0	1	2	54.) overtired
0	1	2	25.) doesn't get along with other kids	0	1	2	55.) overweight
0	1	2	26.) doesn't seem to feel guilty after misbehaving	0	1	2	56.) Physical problems without known medical cause:
0	1	2	27.) easily jealous	0	1	2	a.) aches or pains (not headaches)
0	1	2	28.) eats or drinks things that are not food (don't include sweets) – describe	0	1	2	b.) headaches
0	1	2	29.) fears certain animals, situations or places, (other than school) – describe	0	1	2	c.) nausea, feels sick,
0	1	2	30.) fears going to school	0	1	2	d.) problems with eyes
				0	1	2	e.) rashes or other skin problems
				0	1	2	f.) stomachaches or cramps
				0	1	2	g.) vomiting or throwing up
				0	1	2	h.) other (describe)

Code \_\_\_\_\_

0 = Not True (as far as you know) 1 = Somewhat/Sometimes True 2 = Very True/Often True

0	1	2	57.) physically attacks people	0	1	2	84.) strange behaviour – describe:
0	1	2	58.) picks nose, skin or other part of body – describe	0	1	2	85.) strange ideas – describe:
0	1	2	59.) plays with own sex parts in public	0	1	2	86.) stubborn, sullen, or irritable
0	1	2	60.) plays with own sex parts too much	0	1	2	87.) sudden changes in mood/feelings
0	1	2	61.) poor school work	0	1	2	88.) sulks a lot
0	1	2	62.) poorly coordinated or clumsy	0	1	2	89.) suspicious
0	1	2	63.) prefers being with older kids	0	1	2	90.) swearing or obscene language
0	1	2	64.) prefers being with younger kids	0	1	2	91.) talks about killing self
0	1	2	65.) refuses to talk	0	1	2	92.) talks or walks in sleep
0	1	2	66.) repeats certain acts over and over; compulsions – describe	0	1	2	93.) talks too much
0	1	2	67.) runs away from home	0	1	2	94.) teases a lot
0	1	2	68.) screams a lot	0	1	2	95.) temper tantrums or hot temper
0	1	2	69.) secretive, keeps things to self	0	1	2	96.) thinks about sex too much
0	1	2	70.) sees things that aren't there – describe	0	1	2	97.) threatens people
0	1	2	71.) self – conscious/easily embarrassed	0	1	2	98.) thumb-sucking
0	1	2	72.) sets fires	0	1	2	99.) too concerned with neatness or cleanliness
0	1	2	73.) sexual problems	0	1	2	100.) trouble sleeping
0	1	2	74.) showing off or clowning	0	1	2	101.) truancy/skips school
0	1	2	75.) shy or timid	0	1	2	102.) underactive, slow moving or lacks energy
0	1	2	76.) sleeps less than most kids	0	1	2	103.) unhappy, sad or depressed
0	1	2	77.) sleeps more than most kids during day and/or night – describe	0	1	2	104.) unusually loud
0	1	2	78.) smears or plays with bowel movements	0	1	2	105.) uses alcohol or drugs for non-medical purposes
0	1	2	79.) speech problem – describe	0	1	2	106.) vandalism
0	1	2	80.) stares blankly	0	1	2	107.) wets self during the day
0	1	2	81.) steals at home	0	1	2	108.) wets the bed
0	1	2	82.) steals outside the home	0	1	2	109.) whining
0	1	2	83.) stores up things he/she doesn't need	0	1	2	110.) wishes to be of opposite sex
				0	1	2	111.) withdrawn, doesn't get involved with others
				0	1	2	112.) worries
							113.) please write in any problems your child has that were not listed above;
							a.)
				0	1	2	b.)
				0	1	2	c.)
				0	1	2	

This questionnaire is to be completed by parents/guardians

This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the *past two weeks, including today*. Circle the number beside the statement that you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not chose more than one statement for any group, including Item 16 or Item 18.

**1.) Sadness**

- 0 I do not feel sad
- 1 I feel sad much of the time
- 2 I am sad all the time
- 3 I am so sad or unhappy that I can't stand it

**2.) Pessimism**

- 0 I am not discouraged about my future
- 1 I feel more discouraged about my future than I used to be
- 2 I do not expect things to work out for me
- 3 I feel my future is hopeless and will only get worse

**3.) Past Failure**

- 0 I do not feel like a failure
- 1 I have failed more than I should have
- 2 As I look back, I see a lot of failures
- 3 I feel I am a total failure as a person

**4.) Loss of Pleasure**

- 0 I get as much pleasure as I ever did from the things I enjoy
- 1 I don't enjoy things as much as I used to
- 2 I get very little pleasure from the things I used to enjoy
- 3 I can't get any pleasure from the things I used to enjoy

**5.) Guilty Feelings**

- 0 I don't feel particularly guilty
- 1 I feel guilty over many things I have done or should have done
- 2 I feel quite guilty most of the time
- 3 I feel guilty all the time

**6.) Punishment Feelings**

- 0 I don't feel I am being punished
- 1 I feel I may be punished
- 2 I expect to be punished
- 3 I feel I am being punished

**7.) Self-Dislike**

- 0 I feel the same about myself as ever
- 1 I have lost confidence in myself
- 2 I am disappointed in myself
- 3 I dislike myself

**8.) Self-Criticalness**

- 0 I don't criticise or blame myself more than usual
- 1 I am more critical of myself than I used to be
- 2 I criticise myself for all of my faults
- 3 I blame myself for everything bad that happens

**9.) Suicidal Thoughts or Wishes**

- 0 I don't have thoughts of killing myself
- 1 I have thoughts of killing myself, but I would not carry them out
- 2 I would like to kill myself
- 3 I would kill myself if I had the chance

**10.) Crying**

- 0 I don't cry anymore than I used to
- 1 I cry more than I used to
- 2 I cry over every little thing
- 3 I feel like crying, but I can't

**11.) Agitation**

- 0 I am no more restless or wound up than usual
- 1 I feel more restless or wound up than usual
- 2 I am so restless or agitated that it's hard to stay still
- 3 I am so restless or agitated that I have to keep moving or doing something

**12.) Loss of Interest**

- 0 I have not lost interest in other people or activities
- 1 I am less interested in other people or things than before
- 2 I have lost most of my interest in other people or things
- 3 It's hard to get interested in anything

**13.) Indecisiveness**

- 0 I make decisions as well as ever
- 1 I find it more difficult to make decisions than usual
- 2 I have greater difficulty in making decisions than I used to
- 3 I have trouble making any decisions

**14.) Worthlessness**

- 0 I do not feel I am worthless
- 1 I don't consider myself as worthwhile & useful as I used to
- 2 I feel more worthless as compared to other people
- 3 I feel utterly worthless

**15.) Loss of Energy**

- 0 I have as much energy as ever
- 1 I have less energy than I used to have
- 2 I don't have enough energy to do very much
- 3 I don't have enough energy to do anything

**16.) Changes in Sleep Pattern**

- 0 I have not experienced any change in my sleep pattern
- 1a I sleep somewhat more than usual
- 1b I sleep somewhat less than usual
- 2a I sleep a lot more than usual
- 2b I sleep a lot less than usual
- 3a I sleep most of the day
- 3b I wake up 1- 2 hours early and can't get back to sleep

**17.) Irritability**

- 0 I am no more irritable than usual
- 1 I am more irritable than usual
- 2 I am much more irritable than usual
- 3 I am irritable all the time

**18.) Change in Appetite**

- 0 I have not experienced any changes in my appetite
- 1a My appetite is somewhat less than usual
- 1b My appetite is somewhat greater than usual
- 2a My appetite is much less than before
- 2b My appetite is much more than before
- 3a I have no appetite at all
- 3b I crave food all the time



We are interested to find out about what it is like to have a brother or sister who is ill. When you are answering the following questions we would ask you to try and put yourself in the emotional position of your healthy child and answer the questions from their perspective.

Please read each of the following sentences, put;

a mark like this Yes (✖) if you think this is what your son or daughter would think or feel about the illness

or

a mark like this No (✖) if you do not think this is how your healthy son or daughter would think or feel about the illness

1. Yes ( ) No ( ) He/she feels angry about their brother/sister being ill
2. Yes ( ) No ( ) He/she doesn't want to bother you with their worries
3. Yes ( ) No ( ) He/she wishes that their parents would spend more time with them
4. Yes ( ) No ( ) He/she feels people don't care about how they feel because of the illness
5. Yes ( ) No ( ) He/she can forget that their brother/sister is ill
6. Yes ( ) No ( ) They wish that their parents would spend less time with their brother/sister
7. Yes ( ) No ( ) He/she feels afraid of their brother's/sister's illness
8. Yes ( ) No ( ) He/she can talk to friends about the illness
9. Yes ( ) No ( ) He/she wonders why their brother/sister got sick
10. Yes ( ) No ( ) He/she feels their family does not do as much together due to the illness
11. Yes ( ) No ( ) He/she feels they have too much to do in the house because of the illness
12. Yes ( ) No ( ) He/she can talk to other adults about their brother's/sister's illness
13. Yes ( ) No ( ) He/she wishes they knew someone who understands how they feel
14. Yes ( ) No ( ) He/she can talk to their parents about their brother/sister's illness

15. Yes (    )    No (    )    He/she feels people are more interested in their brother/sister than in them
16. Yes (    )    No (    )    He/she feels their parents ignore them because of the illness
17. Yes (    )    No (    )    He/she can talk to their parents about school work
18. Yes (    )    No (    )    He/she thinks about their brother's/sister's illness
19. Yes (    )    No (    )    He/she wishes there was something they could do about the illness
20. Yes (    )    No (    )    He/she worries about catching their brother's/sister's illness
21. Yes (    )    No (    )    He/she feels sad about their brother's/sister's illness
22. Yes (    )    No (    )    He/she understands why their parents spend more time with their brother/sister
23. Yes (    )    No (    )    He/she feels their friends worry that they can catch the illness

<b>Appendix 5</b>	<b>Child/adolescent completed questionnaires/measures</b> c.) Child Depression Inventory (Kovacs, 1985) d.) Sibling Perception Questionnaire (Carpenter & Sahler, 1991)
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This measure is to be completed by children or adolescents. Kids sometimes have different feelings and ideas. This form lists the feelings and ideas in groups. From each group of three sentences, pick one sentence that describes you **best** for the past two weeks. After you pick a sentence from the first group, go onto the next group. There is no right or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this ( ✕ ) next to the sentence you pick. Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you **best**.

Example:        (    )                      I read books all the time  
                  ( ✕ )                      I read books once in a while  
                  (    )                      I never read books

*Remember, pick out the sentences that describe you best in the **PAST TWO WEEKS**.*

**Item 1**

- (    ) I am sad once in a while
- (    ) I am sad many times
- (    ) I am sad all the time

**Item 2**

- (    ) Nothing will ever work out for me
- (    ) I am not sure if things will work out for me
- (    ) Things will work out for me ok

**Item 3**

- (    ) I do most things ok
- (    ) I do many things wrong
- (    ) I do everything wrong

**Item 4**

- (    ) I have fun in many things
- (    ) I have fun in some things
- (    ) Nothing is fun at all

**Item 5**

- (    ) I am bad all the time
- (    ) I am bad many times
- (    ) I am bad once in a while

**Item 6**

- (    ) I think about bad things happening to me  
   once in a while
- (    ) I worry that bad things will happen to me
- (    ) I am sure terrible things will happen to me

**Item 7**

- (    ) I hate myself
- (    ) I do not like myself
- (    ) I like myself

**Item 8**

- (    ) All bad things are my fault
- (    ) Many bad things are my fault
- (    ) Bad things are not usually my fault

**Item 9**

- (    ) I do not think about killing  
   myself
- (    ) I think about killing myself  
   but I would not do it
- (    ) I want to kill myself

**Item 10**

- (    ) I feel like crying every day
- (    ) I feel like crying many days
- (    ) I feel like crying once in a while

**Item 11**

- (    ) Things bother me all the time
- (    ) Things bother me many times
- (    ) Things bother me once in a  
   while

**Item 12**

- (    ) I like being with people
- (    ) I do not like being with people many times
- (    ) I do not want to be with people at all

**Item 13**

- (    ) I cannot make up my mind  
   about things
- (    ) It is hard to make up my mind  
   about things
- (    ) I make up my mind about things  
   easily

**Item 14**

- (    ) I look O.K.
- (    ) There are some bad things about my looks
- (    ) I look ugly

**Item 15**

- ( ) I have to push myself all the time to do schoolwork
- ( ) I have to push myself many times to do my schoolwork
- ( ) Doing schoolwork is not a big problem

**Item 17**

- ( ) I am tired once in a while
- ( ) I am tired many days
- ( ) I am tired all the time

**Item 19**

- ( ) I do not worry about aches & pains
- ( ) I worry about aches & pains many times
- ( ) I worry about aches & pains all the time

**Item 21**

- ( ) I never have fun at school
- ( ) I have fun at school only once in a while
- ( ) I have fun at school many times

**Item 23**

- ( ) My schoolwork is alright
- ( ) My schoolwork is not as good as before
- ( ) I do very badly in subjects I used to be good in

**Item 25**

- ( ) Nobody really loves me
- ( ) I am not sure if anybody loves me
- ( ) I am sure that somebody loves me

**Item 27**

- ( ) I get along with people
- ( ) I get into fights many times
- ( ) I get into fights all the time

**Item 16**

- ( ) I have trouble sleeping every night
- ( ) I have trouble sleeping many nights
- ( ) I sleep pretty well

**Item 18**

- ( ) Most days I do not feel like eating
- ( ) Many days I do not feel like eating
- ( ) I eat pretty well

**Item 20**

- ( ) I do not feel alone
- ( ) I feel alone many times
- ( ) I feel alone all the time

**Item 22**

- ( ) I have plenty of friends
- ( ) I have some friends but I wish I had more
- ( ) I do not have any friends

**Item 24**

- ( ) I can never be as good as other kids
- ( ) I can be as good as other kids if I want to
- ( ) I am just as good as other kids

**Item 26**

- ( ) I usually do what I am told
- ( ) I do not do what I am told most times
- ( ) I never do what I am told

We are interested to find out about what it is like to have a brother or sister who is ill.

Please read each of the following sentences, put;  
a mark like this Yes (✕) if you agree with the sentence  
or

a mark like this No (✕) if you don't agree with the sentence

1. Yes (    ) No (    )      I feel angry about my brother/sister being ill
2. Yes (    ) No (    )      I don't want to bother my parents with my worries
3. Yes (    ) No (    )      I wish my parents would spend more time with me
4. Yes (    ) No (    )      I feel people don't care about how I feel because of the illness
5. Yes (    ) No (    )      I can forget that my brother/sister is ill
6. Yes (    ) No (    )      I wish my parents would spend less time with my brother/sister
7. Yes (    ) No (    )      I feel afraid of my brother's/sister's illness
8. Yes (    ) No (    )      I can talk to friends about the illness
9. Yes (    ) No (    )      I wonder why my brother/sister got sick
10. Yes (    ) No (    )      I feel my family does not do as much together due to the illness
11. Yes (    ) No (    )      I feel I have too much to do in the house because of the illness
12. Yes (    ) No (    )      I can talk to other adults about my brother's/sister's illness
13. Yes (    ) No (    )      I wish I knew someone who understands how I feel
14. Yes (    ) No (    )      I can talk to my parents about my brother/sister's illness
15. Yes (    ) No (    )      I feel people are more interested in my brother/sister than in me
16. Yes (    ) No (    )      I feel my parents ignore me because of the illness
17. Yes (    ) No (    )      I can talk to my parents about school work



18. Yes (    )    No (    )      I think about my brother's/sister's illness
19. Yes (    )    No (    )      I wish there was something I could do about the illness
20. Yes (    )    No (    )      I worry about catching my brother's/sister's illness
21. Yes (    )    No (    )      I feel sad about my brother's/sister's illness
22. Yes (    )    No (    )      I understand why my parents spend more time with my  
brother/sister
23. Yes (    )    No (    )      I feel my friends worry that they can catch the illness

<b>Appendix 6</b>	<b>Definition of the National Statistics Socio-Economic Classification Definitions (NS-SEC)</b>
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**Table 16** Table showing the nine occupation categories, identified within NS-SEC (2004) which are used as a means of identifying an individual's socio-economic status.

<b>National Statistics Socio-Economic Classification Code (NS-SEC)</b>	<b>Occupational Category (and Examples of Occupation)</b>
NS-SEC 1	<i>Higher Managerial &amp; Occupational Classifications</i> (e.g. managing director, pharmacist, dentist, psychologist and teacher etc.)
NS-SEC 2	<i>Lower Managerial &amp; Professional Occupations</i> (e.g. nurse, hotel manager, product designer and estate agent etc.)
NS-SEC 3	<i>Intermediate Occupations</i> (e.g. clerical workers, administrators, sales and library assistants etc.)
NS-SEC 4	<i>Small Employers &amp; Own Account Workers</i> (e.g. self-employed workers; taxi drivers, driving instructors, agricultural workers and market traders etc.)
NS-SEC 5	<i>Lower Supervisory &amp; Technical Occupations</i> (e.g. train driver, mechanic and gardener etc.)
NS – SEC 6	<i>Semi-Routine Occupations</i> (e.g. fitness instructor, telephonist and market researcher etc.)
NS-SEC 7	<i>Routine Occupations</i> (e.g. tour guide, fishmonger, upholsterer, welder and dental nurse etc.)
NS-SEC 8	<i>Never Worked &amp; Long-Term Unemployed</i> (i.e. unemployed for at least six months)
NS-SEC 9	<i>Unclassified</i> (e.g. housewife)

*Taken From:*

*National Statistics (2004). The National Statistics Socio-Economic Classification User Manual. London: Office for National Statistics.*

<b>Appendix 7</b>	<b>Guidelines for interpreting the T-Scores of the Child Depression Inventory (Kovacs, 1985)</b>
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**Table 17      Guidelines for Interpreting The Child Depression Inventory**

<b>T-Score</b>	<b>Guidelines for a Child/Adolescent Compared to Normative Sample of Similar Age &amp; Gender</b>
Above 70*	Very much above average
66 to 70*	Much above average
61 to 65*	Above average
56 to 60	Slightly above average
45 to 55	Average
40 to 44	Slightly below average
35 to 39	Below average
30 to 34	Much below average
Below 30	Very much below average

\* Identifies T-Scores which are clinically significant

*Taken from*

*Kovacs, M. (2001). Children's Depression Inventory (CDI): Technical Manual. Multi-Health System, Inc.*

<b>Appendix 8</b>	<b>Descriptive &amp; statistical analysis of the data</b>
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## Exploratory Data Analysis

**Table 18**      **Table Showing the Results of the Transformations of the Child Behaviour Checklist Data which Deviated from the Assumptions of Normality**

	Original			Transformation		
	Behaviour Problem Raw Score	Internalising Raw Score	Externalising Raw Score	Behaviour Problem Score	Internalising Score	Externalising Score
<b>Skewness</b>	1.867	2.129	1.625	0.573	0.320	0.226
<b>Std. Error</b>	0.287	0.287	0.287	0.287	0.287	0.287
<b>Kurtosis</b>	5.021	5.822	3.303	0.390	0.502	0.850
<b>Std. Error</b>	0.566	0.566	0.566	0.566	0.566	0.566



## Participant Demographics

**Table 19** Table Showing the Results of the Independent T-Test on Age

Variable	Oncology Group Mean (SD)	Control Group Mean (SD)	T-Value	df	p-value
Age	11.86 (1.9)	11.96 (2.4)	0.60	68	0.952

**Table 20** Table Showing the Results of the Chi-Square Analysis on Gender

	Oncology Group		Control Group		$\chi^2$	df	p-value
	Female	Male	Female	Male			
Sex	7	15	24	24	2.02	1	0.155

**Effect of Background Factors on Healthy Siblings' Psychological & Behavioural Functioning & Adjustment**

**Table 21 Table Showing the Results of the Analysis of Co-Variance Performed on Participants' Child Depression Inventory Data for the Oncology & Control Groups**

Co-Variate	F-Value	df	p-value
Age of Healthy Sibling	3.455	1,66	0.068
Gender of Healthy Sibling	0.081	1,66	0.777
Marital Status of Parents/Guardians	0.527	1,59	0.471
Socio-Economic Status of Parents/Guardians	0.304	1,59	0.584

**Table 22 Table Showing the Results of the Analysis of Co-Variance Performed on Participants' Social Competence T-Scores (Child Behaviour Checklist) for the Oncology & Control Groups**

Co-Variate	F-Value	df	p-value
Age of Healthy Sibling	0.037	1,67	0.848
Gender of Healthy Sibling	0.812	1,67	0.371
Marital Status of Parents/Guardians	0.075	1,60	0.109
Socio-Economic Status of Parents/Guardians	0.136	1,60	0.713

**Table 23 Table Showing the Results of the Analysis of Co-Variance Performed on Participants' Behaviour Problem T-Scores (Child Behaviour Checklist) for the Oncology & Control Groups**

Co-Variate	F-Value	df	p-value
Age of Healthy Sibling	1.433	1,67	0.235
Gender of Healthy Sibling	<b>4.974</b>	<b>1,67</b>	<b>0.029*</b>
Marital Status of Parents/Guardians	3.159	1,60	0.363
Socio-Economic Status of Parents/Guardians	0.073	1,60	0.788

\* Significant at the 0.05 level

**Table 24 Table Showing the Results of the Analysis of Co-Variance Performed on Participants' Internalising Scale T-Scores (Child Behaviour Checklist) for the Oncology & Control Groups**

Co-Variate	F-Value	df	p-value
Age of Healthy Sibling	0.350	1,64	0.556
Gender of Healthy Sibling	<b>4.269</b>	<b>1,64</b>	<b>0.043*</b>
Marital Status of Parents/Guardians	0.010	1,57	0.981
Socio-Economic Status of Parents/Guardians	0.355	1,57	0.553

\* Significant at the 0.05 level

**Table 25**      **Table Showing the Results of the Analysis of Co-Variance Performed on Participants' Externalising Scale T-Scores (Child Behaviour Checklist) for the Oncology & Control Groups**

<b>Co-Variate</b>	<b>F-Value</b>	<b>df</b>	<b>p-value</b>
<b>Age of Healthy Sibling</b>	<b>3.827</b>	<b>1,67</b>	<b>0.042*</b>
<b>Gender of Healthy Sibling</b>	0.531	1,67	0.469
<b>Marital Status of Parents/Guardians</b>	2.137	1,60	0.434
<b>Socio-Economic Status of Parents/Guardians</b>	2.370	1,60	0.814

\* Significant at the 0.05 level

## Hypothesis Two

**Table 26** Table Showing the Percentage of Agreement/Disagreement of Healthy Siblings–Parents/Guardians on Individual SPQ Items

Item on the Sibling Perception Questionnaire	Percentage of Healthy Sibling–Parent/Guardian Agreement	Percentage of Healthy Sibling–Parent/Guardian Disagreement
1.) I feel angry about my brother/sister being ill	64	36
2.) I don't want to bother my parents with my worries	54	46
3.) I wish my parents would spend more time with me	68	32
4.) I feel people don't care about how I feel because of the illness	68	32
5.) I can forget that my brother/sister is ill	55	45
6.) I wish my parents would spend less time with my brother/sister	73	27
7.) I feel afraid of my brother's/sister's illness	59	41
8.) I can talk to friends about the illness	73	27
9.) I wonder why my brother/sister got sick	68	32
10.) I feel my family does not do as much together due to the illness	82	18
11.) I feel I have too much to do in the house because of the illness	68	32
12.) I can talk to other adults about my brother's/sister's illness	59	41
13.) I wish I knew someone who understands how I feel	64	36
14.) I can talk to my parents about my brother/sister's illness	68	32
15.) I feel people are more interested in my brother/sister than in me	82	18
16.) I feel my parents ignore me because of the illness	77	23
17.) I can talk to my parents about school work	81	19
18.) I think about my brother's/sister's illness	86	14
19.) I wish there was something I could do about the illness	100	0
20.) I worry about catching my brother's/sister's illness	86	14
21.) I feel sad about my brother's/sister's illness	91	9
22.) I understand why my parents spend more time with my brother/sister	86	14
23.) I feel my friends worry that they can catch the illness	86	14